

Developmental

Disabilities

Nursing

GUIDEBOOK



DEDICATION

The Developmental Disabilities Nursing Guide (DDNG) guide is dedicated to the Developmental Disabilities Nurses of the Southeastern Region of Pennsylvania who have consistently worked in improving the quality of health services to individuals with I/DD. We would also like to thank the many nurses of the Southeastern Region of Pennsylvania who helped in the development of the DDNG and for whom we hope it will be a useful resource.

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Sincerely,

Jack Toomey, RN, CDDN
Project Leader

DEVELOPMENTAL DISABILITIES NURSING GUIDEBOOK

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SECTION 1

BACKGROUND

Intellectual/Developmental Disability Defined in Pennsylvania

Pennsylvania provides funding for intellectual/developmental disabilities (I/DD) through its Office of Developmental Programs (ODP). The most universally applied definition of what constitutes mental retardation is found in the Diagnostic and Statistical Manual IV [DSM-IV] (American Psychiatric Association, 1994). Pennsylvania's definition of eligibility for mental retardation services differs from the definition in the DSM-IV in only one significant way. According to Pennsylvania the age of onset of mental retardation must occur before the 22nd birthday, concurring with federal funding criteria for Pennsylvania's Medicaid waivers. The DSM-IV states that the age of onset of mental retardation must occur prior to the individual's 18th birthday.

Pennsylvania's definition of mental retardation and the one outlined in the DSM-IV agree in the two most important criteria for a diagnosis. According to both definitions a person must have:

1. A significantly sub average intellectual functioning as determined by an individually administered IQ test (on most standardized tests this would be an IQ score of 70 or below)
and
2. Concurrent impairments in adaptive functioning as determined by a standardized adaptive behavior scale. Impairments must be in at least two of the following areas:
 - Communication
 - Self Care
 - Home Living
 - Social/Interpersonal Skills
 - Use of Community Resources
 - Self Direction
 - Academic Skills
 - Work
 - Leisure
 - Health
 - Safety

At least one percent of the U.S. population has been diagnosed with a developmental disability, an estimate which is considered to be conservative (Developmental Disabilities Nurses Association Study Guide for Developmental Disabilities Nursing, p.1). The criteria for a diagnosis of a developmental disability are broader than those used for a diagnosis of mental retardation. Keep in mind that everyone with mental retardation has a developmental disability, but not everyone with a developmental disability has mental retardation. However, people with mental retardation often have one or more concurrent developmental disabilities. For this reason it is useful to look at what constitutes a developmental disability.

The Developmental Disabilities Assistance and Bill of Rights Act of 1990 Public Law 10-496 defines a developmental disability as a severe, chronic disability of a person who is five years of age or older that:

1. Is attributable to a mental or physical impairment or is a combination of mental and physical impairments
2. Is manifested before the person reaches the age of 22

3. Is likely to continue indefinitely
4. Results in substantial functional limitations in three or more of the areas of major life activity: self-help, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency
5. Reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are lifelong or of extended duration and are individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age five who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided

Therefore, the developmental disabilities nurse, in order to be effective in the habilitation and treatment of people with mental retardation and/or other developmental disabilities must possess a broad range of knowledge and competencies while always being cognizant that:

“Disability is a natural part of the human experience, that does not diminish the right of people with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural and educational mainstream of American society.” (Developmental Disabilities Assistance and Bill of Rights Act 2000, Public Law 106-402, 2000)

Why Have a Guide to Developmental Disabilities Nursing?

To provide useful information about this exciting nursing specialty.

Nursing has a long history of working with people with developmental disabilities, but in the past the specialty of developmental disabilities nursing was ignored in traditional nursing education programs. The Developmental Disabilities Nurses Association has developed a curriculum for this area of specialization, but there is still a lack of codified information about what constitutes developmental disabilities nursing. We hope this guide will provide useful information about this exciting nursing specialty.

To provide a resource for nurses who are new to our specialty as well as nurses with an established intellectual/developmental disabilities (I/DD) practice.

The guide is designed for nurses who support people with I/DD but may also be helpful to others. The authors of the guide practice I/DD nursing in Southeastern Pennsylvania and this document reflects the philosophy of the I/DD service delivery system in Pennsylvania. The authors also work primarily with adults living in small, integrated community residential homes, and their experience with adults is reflected in the guide. Hopefully, developmental disabilities nurses providing care in any settings will be able to use many of the ideas presented here.

To recognize the value of the intellectual/developmental disabilities nurse.

The I/DD nurse, with his/her additional training, knowledge and experience, may motivate, assist, guide, and give exceptional support to individuals with developmental disabilities and their support teams. The I/DD nurse recognizes the whole person who has I/DD and understands that many people in the I/DD system have both physical and behavioral health needs. The I/DD nurse may help to coordinate efforts among health care practitioners, and may also provide direct care. The I/DD nurse must also be able to recognize what aspects of a person's care can be responsibly assigned to others.

To provide some background information on the how the I/DD health services system has evolved in Pennsylvania and in the United States.

The guide offers a definition of the accepted criteria for intellectual disabilities. A short history of I/DD in the United States and Pennsylvania are offered to show how our present system evolved. Various parts of the I/DD system in Pennsylvania and the philosophical basis for the current system are presented. The reference to the Pennhurst litigation is made because of the impact the litigation has had on how people with I/DD receive services in PA today.

To provide some information on various advocacy groups involved in Pennsylvania and across the United States.

This guide offers a listing of various advocacy groups to be used as a resource.

A Short History of the Intellectual/Developmental Disability Service System in the United States and Pennsylvania

(formerly Mental Retardation Service System)

Historically there were only two options for people with I/DD and developmental disabilities: their families provided total care, or they were institutionalized. In the latter half of the 20th century major changes evolved in philosophical and societal thinking about what people thought was best for people with I/DD. This change in consciousness had roots in the civil rights and reform movements of the 1960s and 1970s, but it was also, in part, because the existing I/DD service system began to recognize its own need for reformation.

Terms like humanization, deinstitutionalization, normalization, and mainstreaming came into being. There was a major shift from having people stay in large isolated institutions to providing care in small residential settings in the community. Society began to value the diversity of people with I/DD.

1790-1850: Making the Deviant Non-Deviant: First Attempts at Rehabilitation

People with I/DD were considered deviant, that is, different from other members of society. However, the general outlook toward people with I/DD and developmental disabilities was positive and optimistic. Educational reformers established small residential schools for people with developmental disabilities before the Civil War. These schools were seen as very successful, allowing most residents to return to their communities as independent members of society (White & Wolfensberger, 1969, p.5). People with I/DD were recognized as different, but they were not seen as a burden or threat to society.

Soon, however, this attitude began to change: the cause of I/DD was believed to be the result of immoral or unlawful behavior. The parents must have engaged in “bad behavior” to have a child with disabilities. Society must protect these children and the best way to do this was thought to be by removing them from the source of their “problem,” their families, and placing them in special schools (Developmental Disabilities Nurses Association Study Guide for Developmental Disabilities Nursing, p.55). The special schools stressed discipline and moral training.

1850 -1890: Let the Institutions Begin

In the 1850's the emphasis on “special” schools changed from rehabilitation and education to training. Academic education was abandoned for correction of bad habits and preparation for simple jobs. The small residential schools were soon replaced by large institutions that, for the most part, soon had the goal of becoming self-supporting. The institutions used the people living there as direct care staff and farm hands as much as possible. Treatment could be described as custodial at best and abusive and exploitive at worst.

“Between 1880 and 1890 I/DD began to be considered a major menace and a malignant growth which society in self-protection had to eliminate. During this period laws were passed forbidding marriage and permitting or mandating sterilization and the permanent segregation of the ‘feble-minded’” (White & Wolfensberger, 1969, p.6). It was also at this time that the idea of lifetime institutionalization to prevent reproduction came into being (White & Wolfensberger,

1969, p.6). The routine sterilization of both sexes and segregation of the sexes became the norm. These two practices were mistakenly thought of as a means to prevent all future incidences of I/DD.

1890-1910: Protect Society from the Deviant

In 1893 the first publicly owned and operated facility for the mentally retarded in Pennsylvania was authorized as the Western Institution for the Feeble-minded, the current site of Polk State Center. Western Institution was established at a time when the prevailing attitude toward people who were mentally retarded was shifting from pity and charity to fear and mistrust. Western initiated a 70-year trend of providing residential care for Pennsylvania's retarded citizens in large remote facilities. Prior to 1893 Pennsylvania had purchased care for people with I/DD from Elwyn Institute (a large rural institution) or admitted them to mental hospitals.

Pennhurst Center was created by an act of the Pennsylvania Legislature on May 15, 1903 as the "Eastern Pennsylvania State Institution for the Feeble-Minded and Epileptic." The Legislature appropriated sufficient funds to erect a facility for not fewer than 500 persons and specified that the institution was to be, "entirely and specifically devoted to the reception, detention, care and training of epileptics and of idiotic and feeble-minded persons of either sex" (Pirmann, 1984). Pennhurst Center's later notoriety would become a catalyst for radically changing Pennsylvania's I/DD service delivery system.

In the early 1900s, the idea that different was detrimental was the dominant societal belief. The Binet intelligence test was developed and imported to the United States as a way to identify people whose lack of normal intelligence was not readily apparent. Intelligence testing became a potent weapon against anyone society felt was unworthy. The poor, unwed mothers, prostitutes, Native Americans, and others were labeled "mentally deficient or mentally defective" (Developmental Disabilities Nurses Association Study Guide for Developmental Disabilities Nursing, p.55).

Large custodial institutions proliferated throughout the United States.

1910's: People with I/DD: The Cause of All Societal Problems

It did not take long to go from the belief that anyone who is different is, "detrimental to the general good" to the idea that "mental defectives" were the cause of all social ills. I/DD was seen as the cause of public drunkenness, poverty, and all criminal activity (Pirmann, 1984).

1920s –1940's: People with Developmental Disabilities Seen as Less Than Human

By 1920 there were three public facilities in Pennsylvania (Polk, 1893; Pennhurst, 1903; and Laurelton, 1920) Along with one private institution (Elwyn) these facilities provided residential services for 4,000 mentally retarded people. In 1929 a fourth public facility (Selinsgrove) was opened as a special institution for people with epilepsy.

Research conducted from 1918-1925 showed no linkage between I/DD and criminality. At this time people with developmental disabilities were recognized as no threat to society. However,

there were no changes in the way care was provided for people with developmental disabilities (White & Wolfensberger, 1969, p.6).

The belief that people with developmental disabilities were less than human prevailed because it was necessary to support the less than human conditions of custodial warehousing that existed at the time (Pirmann, 1984). Before the Depression and the World Wars institutions were already under-funded, and because of these events institutions received even less financial assistance from the government. In the 1930s, parents began to organize and form support groups for their families, and some parent groups developed small residential schools to educate their children.

1950's-1960's: The Civil Rights Movement Begins

By 1955 the number of people living at Pennhurst Center had increased and peaked at 3500 with 360 nurses and attendants to provide care for them. Overcrowding at Pennhurst was phenomenal. J. Gregory Pirmann, in "A Short History of Pennhurst Center", uses Quaker Hall, one of the original Pennhurst residential buildings as an example. In the 1980s the maximum regulated capacity for Quaker Hall was 32 people; however, at one time 150 people were living there.

The medical control of epilepsy by 1955 made institutionalization of epilepsy patients unnecessary and so Selinsgrove (which had been established for that purpose) became a facility for people with I/DD. During this time a number of state institutions for people with I/DD opened: White Haven in 1956; Ebensburg in 1957; Hamburg and Western Center, both in 1962; and Cresson in 1964. These institutions were created to reduce the overpopulation existing in other facilities. Despite these new additions the waiting list for admission to state facilities grew from 984 in 1952 to 3,362 by 1965.

The parent groups of the 1930's eventually evolved into The Association for Retarded Children (ARC). The ARC called for an end to the horrific conditions in institutions for the developmentally disabled; they demanded community-based services for their children and that their families be treated with more respect. The ARC issued an Education Bill of Rights for the Retarded Child in 1953, stating that every child with a disability was entitled to an educational program. This eventually led to the passage of the Right to Education Law, which guarantees every child, regardless of disability, the right to a free public education.

In the early 1960's, John F. Kennedy's Administration became an advocate with its Panel on I/DD which demanded further attention to research services and social action for people with developmental disabilities. Largely as a result of this Panel the I/DD Facilities and Community Mental Health Construction Act of 1963 became law, providing finances for research, training of personnel, and construction of facilities to serve people with developmental disabilities.

The civil rights movement also began, demanding equal rights for all minorities. People with developmental disabilities were recognized as a minority with a vocal constituency. The voices of the parents of the disabled began to be heard.

Mid 1960's-Early 1970's: We Can Do Better For People Who Are Disabled

The population of people in state centers peaked in 1967 at approximately 13,500. “Three additional specialized state-operated facilities were opened in the early 1970's (Embreeville in 1973, and Marcy and Woodhaven in 1975) although by this time national, state, and local treatment policies for the mentally retarded were encouraging the development of smaller community based residential services” (Commonwealth of Pennsylvania Department of Public Welfare, 1983).

The deplorable and dehumanizing conditions in institutions became part of the consciousness of social reform. Parents became more organized and assertive and found some allies in human services personnel, mental health professionals, and even superintendents of some institutions. Exposés of large state centers (Willowbrook in New York and Pennhurst in Pennsylvania) received national attention.

Bill Baldini of Philadelphia's WCAU-TV did a five part series on Pennhurst. It raised quite a stir both in Philadelphia and in Harrisburg, revealing that Pennhurst housed 2800 people at the time, more than 800 over its rated capacity (Pirmann, 1984). There was an almost immediate transfer of several hundred elderly residents of Pennhurst to South Mountain Restoration Center, and from there they were placed in “board-and-care homes” throughout the state. A “Family Care Program” was also initiated, and several hundred more Pennhurst residents left under the auspices of that Program (Pirmann, 1984).

In 1970 Pennhurst began to integrate the men and women within the institution's care. Pennsylvania initiated the Community Living Arrangement (CLA) program in 1972. The CLA program was one of the first efforts nationally to provide a community-based system of residential services as an alternative to large scale isolated congregate care settings (Pirmann, 1984). The CLA program incorporated the principal of normalization, which seeks to integrate people with I/DD into the patterns of everyday living normally available to the average person. CLA's provide a full range of community services and allows the people living in them to take full advantage of community resources such as public transportation, recreation and shopping.

The CLA program had an immediate and dramatic effect on the way Pennsylvania provided residential services for its citizens with I/DD. At the end of the 1970-71 fiscal year the Department of Public Welfare (DPW) operated 12 facilities for people with I/DD with a census of 12,434. By 1974 the census in state centers was 11,410 and 879 people with I/DD were now residing in 120 newly established CLA's. (Commonwealth of Pennsylvania Department of Public Welfare, 1983, p.4)

A Consent Agreement was issued in 1972, which said that every child in Pennsylvania must have access to a free public education.

Mid 1970's-1980's: Litigation as a Force to Drive the System

The 1970's saw the custodial model of care replaced by the developmental model of care (Pirmann, 1984). The developmental model had as its basis that everyone can benefit from rehabilitation no matter how severe his or her impairment.

The establishment of the federal Medicaid program and the availability of matching federal funds for facilities, which met federal Intermediate Care Facilities for I/DD (ICF/MR) standards, had a major impact on how large state and private facilities would operate (Pirmann, 1984). The ICF/MR standards brought about many positive changes: they forced most institutions to make many physical improvements; they required a significant decrease in the number of people most institutions could serve; and, most dramatically, they required that each person receive "active treatment." The active treatment requirement necessitated more staffing, the establishment of interdisciplinary teams, expanded documentation requirements and other management initiatives, which helped transform the developmental model from mere words into a reality (Pirmann, 1984).

Another major development in the 1970's was the use of litigation as an agent of change (Pirmann, 1984). Major lawsuits were aimed, firstly, at improving institutional conditions (*Wyatt v. Stickney*) secondly, at forcing diversification of services calling for institutional improvements and deinstitutionalization (*New York ARC v. Carey*) and finally, at the total replacement of institutions by community-based services (*Halderman v. Pennhurst*). The Halderman case was first filed in 1974. It came to trial in 1977, and in March, 1978, Pennhurst was ordered to close. The concept that services should be provided in the "least restrictive" environment was the result of the Pennhurst litigation.

1990's -Present

In 1990, there were 3,900 people with I/DD receiving services in state-operated facilities and over 53,000 people receiving services in the community (MR Bulletin 00-91-05, 1991).

In 1991 an MR bulletin on positive approaches was issued and later that same year "Everyday Lives", Pennsylvania's new philosophical basis for I/DD services, was published. These were landmark documents incorporating the principles of person centered planning with a basic bill of rights for all citizens with developmental disabilities. This also was the foundation for consumer driven services in Pennsylvania.

Person centered planning and essential lifestyle planning are not written policies. They are belief systems that encourage the use of a person's interests, gifts and desires. Positive approaches and essential lifestyle planning embrace each person's differences and recognize the value of diversity to our society as a whole. Positive approaches is focused not on fixing a person but on building competencies, creating opportunities and offering choices that help each person live a fulfilling life. Positive approaches measures success by the satisfaction of the person being supported. Positive approaches and essential lifestyle planning are a means of supporting an individual's goals while giving them the opportunity to contribute to the community in which they live. The self-determination initiative is an extension of the positive approaches movement.

Self-determination not only provides individual plans for people but gives them the ability to choose who will provide the supports necessary to implement the plans. People will not only have an individual plan but an individual budget to support the plan.

Pennsylvania's Office of Developmental Programs has embarked on an ambitious transformation project. These initiatives are aimed at dramatically improving how individuals receive services by supporting and designing an information system to support the new way services are delivered to better serve Pennsylvania's citizens with I/DD.

Community agencies have become skilled at serving all people regardless of the cognitive, physical or mental health issues they may have. The establishment of Health Care Quality Units (HCQU's) across the state serves as a resource to the county I/DD offices and community agencies. The HCQU's help to identify health care needs, provide health care training and help people be better consumers of health care services. The HCQU's are assisting the I/DD service delivery system with one of the biggest challenges today; how to deal effectively with a new geriatric population of people with I/DD.

Today the Commonwealth of PA provides community services for more than 74,000 children and adults with I/DD. As of October 31, 2001, there were 1,727 people receiving services in large state run facilities (PAR, 2001). People can access the system through 46 County MH/MR Units across Pennsylvania. In the 2000-01 fiscal year the Department of Public Welfare's Office of Developmental Program's budget was \$1.8 billion. The total funding for I/DD services projected for fiscal 2005-2006 is \$2.1 billion (OMR Budget, 2005).

Selected Legislation

1963 (US) *Mental Retardation and Community Health Centers Construction Act* established the University Affiliated Programs (UAP) for mental retardation.

1966 (PA) *Mental Health/Mental Retardation Act* provided the means to establish community based services for people with mental retardation.

1971 (US) *Social Security Act* amended to allow Medicaid funds to pay for the services provided by the states in institutions for people with mental retardation and developmental disabilities.

1973 (US) *The Rehabilitation Act* prohibited discrimination on the basis of disability.

1975 (US) *The Education of All Handicapped Children Act* mandated that public schools must provide free/appropriate education, with each child having an Individualized Education Plan (IEP), and where possible, children with disabilities will be educated with children who do not have disabilities.

1975 (US) *The Developmental Disabilities Services and Facilities Assistance and Bill of Rights Act and The Rehabilitation Comprehensive Services and Developmental Disabilities Act 1978* established developmental disabilities councils, protection and advocacy services and a functional definition of developmental disabilities.

1987 (US) *The Developmental Disabilities Act* provided further support for the UAP's.

1987 (US) *The Omnibus Budget Reconciliation Act (OBRA)* required preadmission screening and annual reviews for people with disabilities in Intermediate Care Facilities (ICF) and Skilled Nursing Facilities (SNF's).

1987 *The Older American Act Amendments* included a requirement that agencies on aging include people with developmental disabilities in their plans.

1990 (US) *The Community Living Arrangement (CLA) Amendment* to Medicaid acknowledged and allowed less restrictive options for CLA's.

Special Health Care Requirements for Pennhurst Class Members

Summary of Litigation

The litigation for Pennhurst class members has had dramatic and far-reaching effects on every aspect of how and what services Pennsylvania's Office of Developmental Programs provides for its citizens with intellectual/developmental disabilities (I/DD).

A quick review of the history of the Pennhurst litigation is worthy of our attention. In 1974 a class action lawsuit was filed contending that the residents of Pennhurst were abused and neglected (*Halderman v. Pennhurst State School*). Judge Raymond Broderick of the U.S. District Court for the Eastern District of Pennsylvania issued a landmark ruling in 1977 ordering that the care of individuals with mental retardation should be provided in the "least restrictive setting" (small community based homes vs. large isolated institutions). Judge Broderick's 1985 settlement decree officially closed Pennhurst and stipulated that its former residents must be provided with specified services in the community. In 1994 the Commonwealth of PA and Philadelphia were held in contempt for not providing the specified services outlined in the 1985 decree.

In response to the contempt citation both Pennsylvania and Philadelphia County put in place many supports to help insure that the former residents of Pennhurst would live better lives in the community. The Comprehensive Health Care Plan for Pennhurst class members were submitted to Judge Broderick's Court in 1996. That Plan, together with a Quality Assurance Plan and evidence of many other positive interventions provided by the State and County for the class, led the Court to conclude that the obligations of the 1985 Decree were being met. It also led to the end of active supervision of the Pennhurst class by the Court in 1998. This lawsuit took 24 years to reach a successful conclusion!

Quality Assurance Plan

In 1995 Philadelphia submitted a Quality Assurance Plan for Pennhurst class members and developed Everyday Lives Standards in conjunction with the Quality Assurance Plan. The Standards were a logical expansion of the Everyday Lives principals published by the PA Office for Mental Retardation in 1991. Number 9 of the Everyday Lives Standards outlines the elements of good quality health care, which include:

- A primary care provider, who coordinates care
- Supports to maintain good health care
- Specialists when needed
- Specialty care related to gender and life stage
- A primary care dentist
- Periodic screening for the side effects of medication
- Adaptive equipment in accordance with appropriate evaluation
- Training to use adaptive equipment
- Staff who are trained in appropriate use and maintenance of adaptive equipment
- Staff who are trained to assist in communication about health care

- Appropriate supports to facilitate independence (physical therapist{PT}, occupational therapist,{OT} and other therapies)
- Input into decisions about health care
- No excessive medications
- Readable available records

Comprehensive Health Care Plan for Pennhurst Class Members

The Comprehensive Health Care Plan of 1996 recognized the opportunities and constraints of the existing health care delivery system. The Plan sought to improve upon recent progress made in improving health care and to adopt improved practices to help assure positive health care outcomes for class members. The Plan’s means of achieving these positive health care outcomes was to try to remedy any perceived deficiency in the system to ensure that the health care services available to class members were of good quality while being easily accessible, comprehensive, continuous, coordinated, effective, efficient, satisfying and flexible. The Plan recognized the relationship between good health care and an improved quality of life.

The Plan defined and addressed the following specific health services areas:

- Physical Health
- Dental Health
- Behavioral Health
- Life Stages Health Issues
- Sustaining Quality
- Complaint and Problem Resolution for Health Issues
- Resources and Reimbursement for Health Issues

Philadelphia Coordinated Health Care (PCHC) was named the Health Care Coordinating Agency (HCCA) for the Health Care Plan. In the role of HCCA, PCHC was given primary responsibility for implementation of many of the Plan’s health outcome statements and was available for technical assistance on all parts of the Plan.

The role of the HCCA was further defined to provide support “in developing and maintaining a network of “ vision, dental, family planning, mental health and substance abuse providers,” while providing “health care services coordination, linking the managed care organizations with the residential providers and case managers to ensure continuity and implementation of care plans.” Furthermore the HCCA was instructed to help facilitate the transition from a fee for service health care delivery system to a managed care system while helping to “identify and address gaps in services during the transition period” (Comprehensive Health Care Plan for Pennhurst Class Members, 1996).

Expanding on a rational philosophical base with standards and attention to specific health services areas, the Plan would naturally have a positive impact on the health and quality of life for any individual for which it was implemented. The significance of health care to class members was expressed as follows:

“Adequate medical and dental services support independence in living, productivity in work, quality of life and reduction in morbidity and mortality. Everyone needs good health care” (Comprehensive Health Care Plan for Pennhurst Class Members, 1996).

Thirty-four outcomes with key indicators of compliance were developed. Each outcome was linked to an activity, a responsible party for implementation, a time frame for completion and a measure of compliance. For example, the first desired outcome was: “1. People will have timely access to medical services and appropriate emergency services in communities” (Comprehensive Health Care Plan for Pennhurst Class Members, 1996). The activity associated with the desired outcome was: “A. Encourage enrollment of each eligible person in a managed care organization (MCO) in his community that provides 24 hour coverage or verifies that he can access these services in an alternative way” (Comprehensive Health Care Plan for Pennhurst Class Members, 1996).

The entity responsible for accomplishment of the activity was the HCCA. The time frame for completion was 12-24 months (Comprehensive Health Care Plan for Pennhurst Class Members, 1996). MCO’s “enrollment lists, County Commonwealth and case management monitoring reports” could verify the measure of compliance/completion of the activity (Comprehensive Health Care Plan for Pennhurst Class Members, 1996).

In the physical health area coordination and communication of physical health issues was seen as essential, and using a managed care model for the provision of health services was seen as helpful in improving the communication processes.

The fifth desired outcome was: “5. People will have adequate, appropriate and timely inpatient treatment.” The quality of communication between hospitals and residential providers in the community was examined. A Hospitalization Policy for Pennhurst Class Members was developed and implemented. A key feature of the Hospitalization Policy was the establishment of a point person to serve as a liaison between the residential provider and all other interested parties to improve communication.

The seventh desired outcome was: “7. Residential providers will maintain standard health care records to facilitate communication among PCP’s specialists and staff as may be required by the person’s circumstances or preferences.” Reviews of individual records and outcome 7 led to the development of the Health Information Recording System (HIRS) a standardized medical record keeping system for community residential programs.

Accessing appropriate dental services for people with I/DD had historically been a problem in the community for a variety of reasons: people with long histories of poor dental hygiene; medication side effects on dental health; a lack of available practitioners with experience serving this population; and funding limitations. The fourteenth desired outcome was therefore: “14. Everyone will be able to access needed dental care.”

Behavioral health was another area of major concern. An Independent Physician Review (IPR) for Pennhurst class members found that 39% were receiving psychotropic medications. Given this high percentage there was concern that class members might be receiving psychotropic

medications that they did not really need. This led to desired outcome fifteen: “15. Only people who need psychiatric intervention will receive it.” Comprehensive assessment and differential diagnosis provided by behavioral health professionals experienced with people with mental retardation should be accessed to determine if someone truly has a mental health diagnosis. The IPR and outcome 15 helped with the development and implementation of the Behavioral Health: Team Review of Psychotropic Medications, an invaluable tool for communication among all participants in an individual’s behavioral health team.

Perhaps the biggest challenge to service delivery is the aging population of people with mental retardation, who can expect to experience the same health care challenges as the general population. Two desired outcomes are related to this issue: “17. Each person’s health care needs will be identified with due consideration to life stage issues.” and “18. No one will be relocated because of health care needs without a complete consideration of his wishes, his needs and a range of possible alternatives.” These desired outcomes led to the development and implementation of the *Policy for Pennhurst Class Members as they Age and Nursing Home Policy*.

Other Health Care Supports for Pennhurst Class Members in Philadelphia

Mental Retardation Services (MRS), Philadelphia County’s office for I/DD, established a Special Services Fund (SSF). The SSF is designed to cover reasonable costs of necessary health services, equipment or materials not covered by a class member’s health insurance. PCHC is responsible for the management of the SSF. Please see Appendices.

Philadelphia also contracts with an advocacy agency, Visions for Equality, to do yearly consumer satisfaction reports for class members residing in the county. Part of the survey addresses consumer satisfaction with current health services.

Pennhurst class members also receive an annual review by the Quality Enhancement Support Team (QUEST). This review deals with quality of life issues including community, residential environment, vocational and health issues.

Each person with I/DD requiring acute rehabilitation or skilled nursing must follow the requirements of the Omnibus Budget Reconciliation Act (OBRA). Both Philadelphia and the Southeast Region of ODP must also approve any potential admission. Another safeguard for Philadelphia’s Pennhurst class members was the establishment of the Nursing Home Review Panel (NHRP). The purpose of the NHRP is to review each request for nursing home or rehabilitation admission as well and to determine if alternative in-home supports exist or can be made available. The Panel’s opinion is sought before the admission of any class member to an acute rehabilitation facility or a nursing home. The panel is composed of a physician, nurse, advocate and the Director of MRS or a designee. The panel issues its written recommendations based on the information it receives from the team providing supports for the person in the community.

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SECTION 2

ADVOCACY

Resource List of Advocacy Groups

Southeast Region of Pennsylvania and Statewide

ADAPT (American Disabled for Attendant Programs Today)

(717) 238-0172 work

(717) 238-8663 fax (717) 238-3433 tdd

<http://www.adapt.org/>

Alliance for the Mentally Ill of Pennsylvania

2149 North Second Street

Harrisburg PA 17110

(717) 238-1514

(800) 223-0500

[NAMI Pennsylvania](#)

American Civil Liberties Union (ACLU)

125 South 9th Street

Philadelphia PA 19106

(215) 592-1513

<http://www.aclupa.org/>

American Council of the Blind

Pennsylvania Chapter:

800-736-1410 • www.trfn.clpgh.org/pcb/

National Office:

800-424-8666 • www.acb.org

The American Council of the Blind is the nation's leading membership organization of blind and visually impaired people. It was founded in 1961 and incorporated in the District of Columbia.

The Autism Society of America (ASA)

Greater Philadelphia Chapter:

610-358-5256

www.asaphilly.org

National Office:

1.800.3AUTISM

www.autism-society.org

The mission of the Autism Society of America is to promote lifelong access and opportunity for all individuals within the autism spectrum, and their families, to be fully participating, included members of their community. Education, advocacy at state and federal levels, active public awareness and the promotion of research form the cornerstones of ASA's efforts to carry forth its mission.

Autism Support and Advocacy in PA

243 Lenoir Ave
Wayne, PA 19087
(610) 688-8894

Bureau of Autism Services

Pennsylvania Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675
866-497-6898

Department of Education

Pennsylvania: www.pde.state.pa.us
National: 800-USA-LEARN • www.ed.gov

Disabilities Rights Advocacy Group (DRAG)

P.O. Box 7377
Philadelphia, PA 19101-7377

Telephone: (215) 477-4956

www.draginc.com

Founded in 1989, the Disabilities Rights Advocacy Group (D.R.A.G.) aims to empower the disabled population and, to that effect, create awareness among the able-bodied citizenry. D.R.A.G is organized to be an avenue where disabled persons can address and seek recourse to issues concerning discrimination in housing, public accommodation, education and total accessibility to federal, state, municipal and public buildings.

Disability Rights Networks

1315 Walnut Street
Philadelphia, PA 19107

Disabled In Action of PA, Inc. (DIA)

125 South 9th Street, Suite 700
Philadelphia, PA 19107
(215) 627-7255 v/tty

Epilepsy Foundation of America

Eastern Pennsylvania Chapter:
800-332-1000
215-629-4997

www.epilepsyfoundation.org

The Epilepsy Foundation is a national, charitable organization, founded in 1968 as the Epilepsy Foundation of America. The only such organization wholly dedicated to the welfare of people with epilepsy, our mission is simple: to work for children and adults affected by seizures through research, education, advocacy and service.

Health Care Quality Units (HCQU's)

Health Care Quality Units (HCQUs) serve as a resource for the overall health status of individuals with developmental disabilities in the counties in which they are funded. HCQUs work to support and improve the state MR community system by building capacity and competency to meet the physical and behavioral health care needs of people with developmental disabilities living in Pennsylvania. The primary activities of HCQUs include: assessment of individual health and systems of care; providing clinical health care expertise to counties and residential and day program providers; health related training; integrating community health care expertise to counties and residential and day program providers; health related training; integrating community health care resources with state and regional quality improvement structures and processes and health advocacy. The ultimate goal of the HCQUs is to assure that the individuals served by county developmental disabilities programs are as healthy as they can be, so that each individual can fully participate in community life.

Southeast Region HCQU:
Philadelphia Coordinated Health Care
1601 Market Street
5th Floor
Philadelphia, PA 19103
215-546-0300
www.pchc.org

Institute on Disabilities/University Affiliated Program (UAP)

Temple University
423 Ritter Annex
13th & Cecil B. Moore Avenue
Philadelphia PA 19122
www.temple.edu/instituteondisabilities

The Institute on Disabilities at Temple University is one of the sixty-one University Centers for Excellence in Developmental Disabilities funded by the Administration on Developmental Disabilities U.S. Department of Health and Human Services. The mission of the Institute on Disabilities is that, in partnership with people with disabilities, families and allies from diverse cultures, we work to change systems so that people can live, learn, work and play in the communities of their choice. This mission is accomplished through training, technical assistance, services and supports, research, dissemination, and advocacy.

Learning Disabilities Association of America

Toomey Building Eagle, Box 208
Uwchland, PA 19480
(610) 458-8193
<http://www.ldanatl.org/Pennsylvania/Index.html>

LDA is the only national organization devoted to defining and finding solutions for the broad spectrum of learning disabilities. LDA is the largest non-profit volunteer organization advocating for individuals with learning disabilities. LDA has 50 state affiliates and more

than 600 local chapters in 50 states, Washington DC, and Puerto Rico. Membership totals more than 50,000.

Liberty Resources

www.libertyresources.org

We are a non-profit, consumer driven organization that advocates and promotes Independent Living for persons with disabilities. More than fifty percent of our board as well as fifty percent of our employees are persons with disabilities.

Networks for Training and Development, Inc.

1601 Market St, 6th Floor
Philadelphia, PA 19103
(215) 546-4111

Parent Education Network (PEN)

800-522-5827 • www.parentenet.org

PEN is Pennsylvania's statewide Parent Training and Information Center. Much of the information included in this site is designed to support Pennsylvania parents of children with special needs, but information and links are included on Federal Special Education, National Disability Issues and Resources, Special Education Legal Links, Transportation, and Travel that will also pertain to parents and individuals with disabilities in other states.

Parent's Involved Network (PIN)

800-688-4226 • www.pinofpa.org

Parents Involved Network of Pennsylvania (PIN) is an organization that assists parents or caregivers of children and adolescents with emotional and behavioral disorders. PIN provides information, helps parents find services and will advocate on their behalf with any of the public systems that serve children. These include the mental health system, education, and other state and local child-serving agencies.

Parent to Parent of Pennsylvania/ Special Kids Network

800-986-4550 • www.parenttoparent.org

Parent to Parent of Pennsylvania is a network created by families for families of children and adults with special needs. We connect families in similar situations with one another so that they may share experiences, offer practical information and/or support.

Pennsylvania Association of Resources for People with Mental Retardation (PAR)

1007 North Front St
Harrisburg, PA 17102
(717) 236-2374

Pennsylvania Coalition of Citizens with Disabilities

101 S Second St, Ste 4
Harrisburg, PA 17101
(717) 238-0172 voice
(717) 238-3433 TT
(800) 432-3060

Pennsylvania Developmental Disabilities Council

717-787-6057 • www.padcc.org

The Pennsylvania Developmental Disabilities Council is a group made up of people with disabilities, family members, advocates, and state department representatives who work to create favorable conditions for people with developmental disabilities and their families in the Commonwealth.

Pennsylvania Education Law Center

215-238-6970 • www.elc-pa.org

The Education Law Center (ELC) is a non-profit legal advocacy organization dedicated to ensuring that all of Pennsylvania's children have access to a quality public education.

Pennsylvania Elks

Home Service Program

Cranberry Lodge No. 2249 (W)

111 Concord Way

Cranberry PA 16006

724-776-3175

The Elks Home Service Program is a free service that is available in any of the 67 counties comprising the Commonwealth of Pennsylvania. The staff is expert in finding services that exist for people with developmental disabilities. They know the rights of the person with the disability as well as those of their family. This in-home consultation service is primarily financed by the 110 Pennsylvania Elks Lodges across the state.

Pennsylvania Health Law Project

800-274-3258 • www.phlp.org

PHLP is a nationally recognized expert and consultant on access to health care for low-income consumers, the elderly, and persons with disabilities. For more than a decade, PHLP has engaged in direct advocacy on behalf of individual consumers while working on the kinds of health policy changes that promise the most to the Pennsylvanians in greatest need.

Pennsylvania Legal Services

118 Locust Street

Harrisburg, PA 17101-1414

(717) 236-9486

(800) 322-7572

Pennsylvania Mental Health Consumers' Association

4105 Derry Street

Harrisburg, PA 17111

(717) 564-4930 or (800) 887-6422

Fax 717-564-4708

Website- www.pmhca.org

E-mail - pmhca@pmhca.org

Pennsylvania Parents and Caregivers Resource Network

888-5-PARENT • www.ppcrn.org

We are a statewide cross-disability, grassroots network that supports parents' and caregivers' efforts to help their children and adult family members with developmental disabilities. PPCRN helps them to form local groups and to network with other parents in their regions and across the state. We promote inclusionary practices in all areas of life among parents and caregivers of children and adults with developmental disabilities.

Pennsylvania Society for the Advancement of the Deaf (PSAD)

www.psadweb.org

PSAD fights discrimination and public misconceptions in our everyday lives by lobbying for the establishment of a deaf/hard of hearing bill of rights with local, state, and federal government through different agencies and organizations.

Pennsylvania Special Education Consult Line

800-879-2301

www.pde.state.pa.us/special_edu/site/default.asp

Help for families and advocates of children with special needs about special education regulations, school related concerns, and procedural safeguards.

Pennsylvania State Independent Living Center (SILC)

108-110 North 2nd Street

Harrisburg, PA 17101

(717) 236-2400

Pennsylvania Vocational Rehabilitation Agency

800-622-2842 • www.dli.state.pa.us

Coordinates and provides counseling, evaluation, and job placement services for people with disabilities.

Speaking for Ourselves

610-825-4592 • www.speaking.org

Speaking For Ourselves, a non-profit organization, is a pioneer in self-advocacy for people with disabilities. Our mission is to find a voice for ourselves. Teach the public about the needs and wishes and potential of people with disabilities. Speak out on important issues and Support each other through sharing, leadership development and helping and encouraging each other.

United Cerebral Palsy Association (UCPA)

925 Linda Lane

Camp Hill, PA 17011

(717) 761-6129

<http://www.ucpa.org/>

Visions for Equality

215-923-3349

www.visionforequality.org

A non-profit organization that was established in 1996 for the purpose of providing monitoring and advocacy services for people with mental retardation and their families. Vision for Equality's mission is to assist and empower people with disabilities and their families to seek quality and satisfaction in their lives and equal access to supports and services. Five major program areas are: 1. Embreeville Consumer and Family Satisfaction Teams; 2. Court-related and General Advocacy; 3. a Training Department; 4. The Pennsylvania Waiting List Campaign including community education services; 5. Independent Monitoring for Quality (IM4Q).

Resource List of Advocacy Groups

National

American Association on Intellectual and Developmental Disabilities (AAIDD)

444 North Capitol Street, NW
Suite 846
Washington, D.C. 20001-1512
202-387-1968 or 1-800-4243688
Fax: 202-387-2193
www.aaid.org

Americans with Disabilities Act Information

www.usdoj.gov

The Arc

301-565-3842 • www.thearc.org

The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families. The association also fosters research and education regarding the prevention of mental retardation in infants and young children. The Arc is people - people with mental retardation and related developmental disabilities, parents and other family members, and friends of people with mental retardation and professionals who work with them.

CONNECT Information Service

800-692-7288

The Consortium for People with Developmental Disabilities

202-783-2229

www.c-c-d.org

The Consortium for Citizens with Disabilities is a Coalition of national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. Since 1973, the CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

Council for Exceptional Children

703-620-3660 • www.cec.sped.org

Pennsylvania CEC: www.pfcec.org

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted. CEC advocates for appropriate governmental policies, sets professional standards, provides continual professional

development, advocates for newly and historically underserved individuals with exceptionalities, and helps professionals obtain conditions and resources necessary for effective professional practice.

Easter Seal Society

SE Pennsylvania:

www.easterseals-sepa.org

National:

312-726-6200 • www.easter-seals.org

Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 80 years. Whether helping someone improve physical mobility, return to work or simply gain greater independence for everyday living, Easter Seals offers a variety of services to help people with disabilities address life's challenges and achieve personal goals.

EDLAW

www.edlaw.net

The EDLAW Center was established to provide assistance on a systemic level to attorneys who represent parents of children with disabilities. It is premised on the recognition that, while securing an appropriate education for any single child with a disability is important, changes on a systemic level are necessary to enable all children with disabilities to obtain the free appropriate public education promised them by the law.

IDEA Practices

877-CEC-IDEA • www.ideapractices.org

The IDEA Partnerships are four national projects funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) to deliver a common message about the landmark 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA). The IDEA Partnerships, working together for five years, inform professionals, families and the public about IDEA '97 and strategies to improve educational results for children and youth with disabilities.

National Down Syndrome Congress

1-800-232-NDSC • www.ndscenter.org

The purpose of the NDSC is to promote the interests of persons with Down syndrome and their families through advocacy, public awareness, and information dissemination on all aspects of Down syndrome. The NDSC is financially supported primarily through membership dues and individual contributions.

National Down Syndrome Society

800-221-4602 • www.ndss.org

The National Down Syndrome Society was established in 1979 to ensure that all people with Down syndrome have the opportunity to achieve their full potential in community life. Since that time, this not-for-profit organization has become the largest non-governmental supporter of Down syndrome research in the United States.

National Organization on Disability

202-293-5960 • www.nod.org

The National Organization on Disability, celebrating its 20th anniversary in 2002, promotes the full and equal participation and contribution of America's 54 million men, women and children with disabilities in all aspects of life.

Reed Martin, JD – Special Education Law

www.reedmatin.com

Reed Martin is an attorney with over 34 years experience in special education law and recognized as one of the nation's leading experts.

Tourette Syndrome Association

718-224-2999 • www.tsa-usa.org

Founded in 1972 in Bayside, New York, the Tourette Syndrome Association, Inc., or TSA, is the only national voluntary non-profit membership organization in this field. Its mission is to identify the cause of, find the cure for and control the effects of this disorder.

United Cerebral Palsy

800-872-5827 • www.ucpa.org

UCP is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of persons with any disability. As one of the largest health charities in America, UCP's mission is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities.

US Office of Special Education Programs

202-205-5507 • www.ed.gov/offices/OSERS/OSEP/

OSEP is dedicated to improving results for infants, toddlers, children and youth with disabilities ages birth through 21 by providing leadership and financial support to assist states and local districts.

Wright's Special Education Law

www.wrightslaw.com

Parents, advocates, educators, and attorneys come to Wright's Law for accurate, up-to-date information about advocacy for children with disabilities. You will find hundreds of articles, cases, newsletters, and resources about special education law and advocacy in the Advocacy Libraries and Law Libraries.

Introduction to the Arc
(The Arc merged with the American Association on Intellectual and
Developmental Disabilities [AAIDD] on 1/1/07)

Please note that all information in quotations was taken from The Arc of the United State website at <http://www.thearc.org>, accessed March 4, 2008.

The Arc of the United States

“The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families.”

Mission Statement

“The Arc of the United States works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community.”

Location and Information

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
(301) 565-3842
(301) 565-5342 (fax)
Email: Info@thearc.org
www.thearc.org

Policy Statements

“The Arc’s policy statements address critical issues related to rights, treatment, services and programs for children and adults with mental retardation and their families.” For a complete list of policy statements, please contact The Arc of the United States or visit their website (www.thearc.org). We have included the policy statements listed below in the Appendix:

1. Advocacy
2. Aging
3. Health Care
4. Inclusion
5. Protection
6. Quality of Life
7. Rights
8. Self-Determination
9. Sexuality

REFERENCES

- The Arc of the United States. <http://www.thearc.org>

SECTION 3

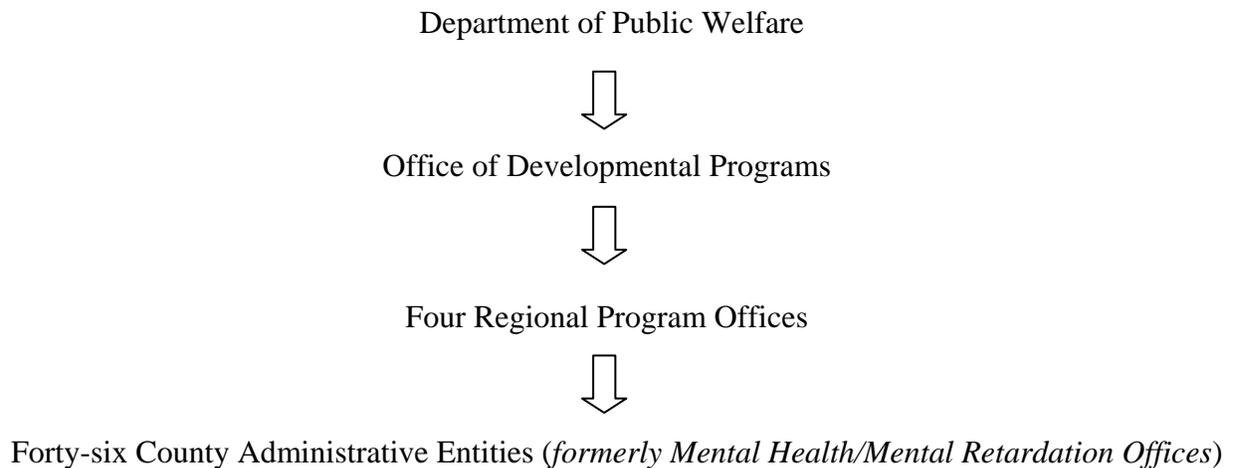
O **VERVIEW OF PENNSYLVANIA INTELLECTUAL/ DEVELOPMENTAL DISABILITIES SERVICE DELIVERY SYSTEM**

Pennsylvania's Intellectual/Developmental Disabilities Service Delivery System

Overview

Pennsylvania provides funding for people with I/DD through its Office of Developmental Programs (ODP). In order to be eligible to register for services through ODP, the age of onset of I/DD must occur before the 22nd birthday. This concurs with federal funding criteria for Pennsylvania's Medicaid waivers.

Flow Chart of Service



Pennsylvania Office of Developmental Programs Demographics

(Pennsylvania Department of Public Welfare, 2003)

Services

Approximately 79,649 people registered for services

Approximately 20,013 children receive early intervention services

Approximately 4,452 total licensed facilities

Living Arrangements

- 57% live with a relative
- 12% live in Community Living Arrangement (CLA)
- 10% live in their own homes
- 4% are in family living
- 3% live in intermediate Care Facilities (ICFs)
- 2% live in a state MR facility
- 10% are classified as other

Age

- 48% children ages 0-17
- 46% adult ages 18-59
- 6% elderly 60+

Budget

The 2007-2008 Commonwealth of Pennsylvania budget allocates \$1.8 B in state and federal funds to community-based I/DD services.

Southeastern Pennsylvania Intellectual/Developmental Disabilities Service System

Southeastern Office of Developmental Programs
(20,000 people registered for services)



Five County Administrative Entities
(Bucks, Chester, Delaware, Montgomery, and Philadelphia)



Approximately 100 Provider Agencies



Approximately 3,000 Community Residential Programs

Description of Community Residential Programs

There are three major types of residential programs in Pennsylvania for adults with intellectual/developmental disabilities (I/DD):

Intermediate Care Facility (ICF): Licensed under the 6600 regulations, these facilities are monitored by supports coordinators and annually by a team from the Department of Health (DOH). Supervision in ICFs is 24 hours a day/ 7 days a week (24/7). Staffing varies contingent upon needs of individuals supported in each program. Small ICFs have fewer than eight people in each home. Large ICFs provide support for more than eight people and may be provided in large institutional settings. ICFs require nursing support, which helps to provide a quarterly medical review and annual plan. The supporting agency must provide evidence of “active treatment” for each person. There are stringent rules for documentation of “active treatment.”

Community Living Arrangement (CLA): Licensed under the 6400 regulations, CLA’s are monitored monthly by supports coordinators and annually by ODP licensing staff. People in these programs reside in the community in individual homes/apartments. Almost all homes provide 24/7 supervision. Staffing is based on the individual needs of the people supported in each program. Most CLA’s serve one to four people. There is no requirement for nursing support, but it is viewed as highly desirable in helping to meet the health needs of people in CLA’s, especially as they grow older and their health concerns can become more challenging.

Supported Living: There is some variety in supported living programs. Most are not licensed under any specific regulations. However, family living, which is sometimes also called companion living or life sharing, is licensed under the 6500 regulations. Supports coordination offers some monitoring of services. Up to twenty hours of staffing are generally available in supported living programs and services are based on individual need to help a person succeed in living in the community. An agency, a family or a companion may provide supports. There is no requirement for nursing support in supported living programs, but it is viewed as highly desirable in helping to meet the health needs of people in supported living, especially as they grow older and their health concerns may become more challenging.

Pennsylvania Regulation and Licensing Instruments

The Commonwealth of Pennsylvania, through the Department of Public Welfare, established a monitoring system for individuals receiving supports provided by state and federal funds. This system ensures health, safety and well being of individuals with intellectual/developmental disabilities (I/DD). It is extremely important that nurses working in the field of developmental disabilities are familiar with the regulatory process.

The following is a list of different regulation titles. Copies of the regulations are available by request from regional Offices of Developmental Programs.

- **Chapter 2380** Licensing Inspection Instrument for Adult Training Facility Regulations
- **Chapter 2390** Licensing Inspection Instrument for Vocational Training
- **Chapter 3800** Child Residential and Day Treatment Facilities
- **Chapter 6400** Licensing Inspection Instrument for Community Homes for Individuals with Mental Retardation Regulations
- **Chapter 6500** Licensing Inspection Instrument for Family Living Homes Regulations
- **Chapter 6600** Interpretive Guidelines for Intermediate Care Facilities For the Mentally Retarded

Individual Support Plan (ISP) Process

The Individual Support Plan (ISP) is a plan for an individual developed by him or her and the people they choose. Information gathered for this plan includes an assessment of health and safety issues, individual preferences, priorities and needs that promote a person-centered planning process to help develop outcomes and positive approaches in supporting the individual. The focus includes three major areas: home, work, and community life.

The process involves the person's team, and may include residential staff, day program staff, nursing, supports coordinator, behavior specialist, family members and anyone the individual desires. This team meets at least annually to discuss any changes, additions, or deletions to supports that may be needed or wanted by the individual. If for some reason the person is unable to participate in this meeting (i.e., they are in the hospital), the team will meet to discuss supports they feel the individual would want or need on his/her behalf.

The actual ISP documentation is completed by the supports coordinator, with input from all team members. It is updated at least annually but can be amended as the need arises.

Agency Nurse Responsibilities within Risk Management

Incident reporting through the Home and Community Services Information System (HCSIS) is the responsibility of agencies providing services to individuals with intellectual/developmental disabilities (I/DD). Processes within each provider agency should be in place describing the role of the agency nurse. The expectations for agency nurses working within HCSIS include (but are not limited to) the following:

- The nurse should be involved in risk management strategies and meetings.
- The nurse should be available to assist the agency's risk/quality manager to develop standards for reporting health trends and implementing programs to address these issues.
- The agency nurses should be notified of health care related incidents and follow-up regarding those incidents.
- The nurse should be available to discuss individual health risk issues with supports coordination.

Pennsylvania Health Care Quality Units

The Pennsylvania Office of Developmental Programs (PA-ODP) has established Health Care Quality Units (HCQUs) across the state of Pennsylvania. The HCQU for the Southeast Region of Pennsylvania is Philadelphia Coordinated Health Care (PCHC). This HCQU serves Bucks, Chester, Delaware, Montgomery, and Philadelphia counties. The primary mission of PCHC is to improve the quality and quantity of health related services for people diagnosed with intellectual/developmental disabilities (I/DD). PCHC provides clinical consultations, technical assistance, training, and resource development to individuals with mental retardation, their families, service providers, and health care professionals. PCHC does not provide direct health care services, but strives to enhance those services which already exist in the Southeast Region of Pennsylvania by stressing the importance of employing a holistic approach to meeting each individual's health care needs. PCHC works extensively with the local managed care organizations and provides support to individuals with I/DD in securing health care services through the managed care health system. PCHC has established many innovative programs to support the I/DD service delivery system and also works closely with the state and regional offices of I/DD in designing its supports.

Information regarding HCQUs is available on the PA-ODP website and is included below:

Health Care Quality Units

HCQU Specifications

Section 1. Vision Statement

The pursuit of quality is the fundamental driving principle in Pennsylvania's developmental services systems. Pennsylvania's community I/DD system strives to provide each individual with the finest community development services in the nation. To achieve this vision, Health Care Quality Units will provide leadership and coordination to enable county MR programs, in collaboration with the state Office of Developmental Programs (ODP), formerly the Office of Mental Retardation, to assure the highest achievable level of physical and behavioral health to individuals served.

Section 2. Mission Statement

Health Care Quality Units [HCQUs] serve as the entity responsible to county I/DD programs for the overall health status of individuals receiving services in the county programs. HCQUs work to support and improve the state I/DD community system by building capacity and competency to meet the physical and behavioral health care needs of people with developmental disabilities living in Pennsylvania. The primary activities of HCQUs include: assessment of individual health and systems of care; providing clinical health care expertise to counties and residential and day program providers; health related training; integrating community health care expertise to counties and residential and day program providers; health related training; integrating community health care resources with state and regional quality improvement structures and processes and health advocacy. The ultimate goal of the HCQUs is to assure that the individuals

served by each county MR program are as healthy as they can be, so that each individual can fully participate in community life.

Section 3. Purpose

The quality of health care is directly related to important safety issues for people residing in communities. The issues of health care and safety are receiving careful scrutiny both in Pennsylvania and throughout the country as various groups evaluate the quality of life that community living affords. This scrutiny has surfaced problems in some states and serves to highlight the importance of careful planning and monitoring.

Not all communities have health care providers who are knowledgeable about the unique health care issues that face people with developmental disabilities and not all are practiced in communicating effectively with residential provider agencies, case managers and planning teams. Residential providers, families, and others who support people in community settings need resources to help them solve health care problems with doctors, hospitals and other health care providers. As the use of the HMOs grows, they, too, require assistance to understand and address the unique needs of people with developmental disabilities.

The development of a HCQU in Pennsylvania helped address these issues. Other states are now looking at that experience as a potential model for forging connections to health care services for people with I/DD living in communities. ODP recognized the advantages of the original HCQU (Philadelphia Coordinated Health Care) and promoted this model across the state.

HCQU Primary Focus:

- Individual Outcomes
- Physical Health
- Behavioral Health
- Systems of Care

Section 4. HCQU Core Functions

Additional registered nurses, licensed practical nurses, social workers and/or unlicensed developmental disabilities professionals as needed to efficiently and effectively carry out the Core Functions outlines in Section 3.

Last modified on: October 9, 2007

Introduction to Developmental Programs Bulletins

The Commonwealth of Pennsylvania Department of Public Welfare distributes Developmental Programs Bulletins (previously known as Mental Retardation [MR] Bulletins) regarding various topics of concern. The content of Developmental Program (DP) Bulletins serves multiple purposes to:

- Provide interpretation, clarification or explanation of existing regulations
- Provide guidelines for a new program, direction or policy that does not require regulation
- Provide operating procedure, direction and general program information for state centers
- Provide a new program direction or policy in response to federal statute or regulations, state statute, judicial decision, or court order

DP bulletins are distributed to those facilities/agencies contained within the scope of the bulletin on a need-to-know basis. They can also be obtained through the Department of Public Welfare or accessed via the internet at

<http://www.dpw.state.pa.us/PubsFormsReports/NewslettersBulletins/003673169.aspx>.

Listings of the DP and/or MR bulletins that remain in effect are found in the Appendix.

Introduction to Everyday Lives Standards Pennsylvania's Philosophy of Care

Everyday Lives was published in 1991. This historic document reflects the values and vision of people with disabilities, their families and Office of Developmental Programs (ODP) staff who worked together on an equal basis to identify what is important to people with disabilities and what supports would be necessary to obtain what was identified as important. Since its publication the values and vision expressed in *Everyday Lives* have provided the framework for planning, policy development, service design and all related activities in Pennsylvania's Developmental Programs service system.

In the fall of 2000, the Self-Determination Consumer/Family Group was asked to review developments in the system since the 1991 publication of *Everyday Lives* and to create an updated edition. *Everyday Lives: Making it Happen* is the product of this group's work. The 2001 publication of *Everyday Lives: Making it Happen* reaffirms the values of choice and control, individual freedom and safety, individuality and relationships, success and the stability and recognition that comes from making a contribution to the community. The new edition introduces the values of collaboration, quality, mentoring and accountability and also identifies challenges for the future.

The *Everyday Lives* document can be found in the Appendix or on the Internet at http://www.dpw.state.pa.us/Resources/Documents/Pdf/Publications/everyday_lives.pdf. The Everyday Lives Standards and Person Centered Planning information follows.

Everyday Lives Standards

This list was born of the effort to join the ambitious principles, announced in the foundation document, “Everyday Lives”, PA Department of Welfare June, 1991 and expanded upon in strategic planning work across Philadelphia County. It is a list of basic standards, expressed as outcomes to apply to delivery of services and supports. It is deliberately brief to allow for the exercise of common sense to permit the wide flexibility that attending individuality requires. Listed under each standard are indicators and guidelines, which will assist in evaluating whether these standards are being met.

The following are important and meaningful expressions of the values underlying quality service delivery

1. Every person has a plan of service and it is being followed:
 - The process is more person-centered.
 - The plan is mailed within 30 days of the team meeting.
 - The plan is implemented within 60 days of the team meeting.
 - The plan is followed and changed as needed.
2. People have opportunities to make choices about:
 - People with whom to live.
 - Community in which of live.
 - Possessions and furnishings.
 - Food and meal times.
 - Job or daytime activities.
 - Spiritual activities.
 - Leisure activities.
 - Friends and family relationships.
 - Normal rhythms and routines of life.
 - Valued adult roles.
3. People have support for the choices they make by being provided:
 - Exposure to a variety of experiences to inform choice-making.
 - Adequate, trained caregivers.
4. People have the chance to be heard:
 - In the individual planning process.
 - In the selection and training of caregivers.
5. People live in safe homes that are:
 - In neighborhoods that meet their needs and desires.
 - In good repair.
 - Accessible to meet their needs.
6. People have protections from harm.
 - Physical and psychological abuse and neglect are prohibited.
 - Unnecessary restraint and seclusion are prohibited.
7. People have opportunities for privacy including:
 - Time and space to be by themselves.
 - Time and space to be with friends.
 - Private access to mail and phones.
 - Support to read mail and use phones when wanted.
8. People have personal possessions and funds. This means:
 - People’s possessions and funds are safe.
 - People have access to their possessions and funds.
 - People have support to manage funds.
 - People have adequate clothing.
9. People have quality health care including:

- A primary care provider, who coordinates care.
 - Supports to maintain good health
 - Specialists when needed.
 - Specialty care related to gender and life stage.
 - A primary care dentist.
 - Periodic screening for side-effects of medication.
 - Adaptive equipment in accordance with appropriate evaluation.
 - Training to use adaptive equipment.
 - Staff who are trained in appropriate use and maintenance of adaptive equipment.
 - Staff who are trained to assist in communication about health care.
 - Appropriate supports to facilitate independence (PT, OT, etc.).
 - Input into decisions about health care.
 - No excessive medications.
 - Recertification of psychotropic medications every 90 days by physicians.
 - Independent review of medications.
 - Readable, available records.
10. People who want jobs have them, and:
- Have supports to find and keep jobs.
 - For people who do not want jobs or who are retired, opportunities for alternative, integrated, community activities are provided.
 - Have supports to change jobs or providers when desired.
11. People have opportunities and supports to pursue things they like to do:
- To contribute to their communities
 - To practice religion or not.
 - To establish and maintain relationships with family and friends.
 - To vote and participate in local government activities.
12. People have Case Managers:
- Who visit their homes or work sites regularly
 - Who follow and change the individual plan, as needed.
 - Who have the skills and training to support them.
 - Who assist in communication with supporters, family, and other significant people.
 - Whose responsibilities include no more than 25 people.
 - Whose receive at least three (3) days of pre-service and one (1) of annual training.
13. People have access to a dispute mediation process.
14. People have quality supports and services, which means:
- Staff are trained.
 - Providers have technical assistance to address difficult challenges.
 - Providers' contracts include incentives for exceeding requirements, sanctions for failure to perform, and requirements for evaluation.
15. People have access to adequate transportation:
- That is stigma free.
 - That is accessible
 - That is dependable
 - That supports work and activities.
- Philadelphia Quality Assurance Plan,
09/18/95***

Person Centered Planning

Person Centered Planning is not a written policy. It is a belief and value system that encourages the use of a person's interests, gifts, and desires.

The person centered planning philosophy is used in writing each individual's support plan.

Topics include, but are not limited to:

- What are positive things about that individual?
- What are his/her favorite activities?
- What is important to that individual?
- What do others need to know, and what should they do and not do?
- What would happen on a good day?
- Describe the person's current relationships.
- What community activities would the person like to participate in?
- What health promotion strategies can be utilized?

Major goals when writing the plan deal with how to support the individual over time using community networks. Promoting choice is encouraged in work, community, and home settings.

Person centered planning can be summarized as using a proactive, team approach to enhance an individual's future in the community and to ensure that the individual's physical, emotional, and social needs are planned for appropriately on a yearly basis.

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SECTION 4

PROFESSIONAL CERTIFICATION IN DEVELOPMENTAL DISABILITIES NURSING

Philosophy of Nursing Care

As nurses in the specialty of developmental disabilities nursing we care for individuals in non-hospital settings, most often in the communities where we make our homes. We support the development and well-being of individuals throughout the life cycle and promote a holistic approach to nursing. We promote self-responsibility regarding health and well being among those we care for and their caregivers. We promote safety in the environment. We practice the basic ethical principles of health in our concern for the welfare of others (altruism), doing good (beneficence), avoiding harm (non-maleficence), treating people fairly (justice), and honoring self-determination (autonomy). We adhere to the Nursing Code and Standards of Nursing Practice. Our responsibilities are many and include identification of unmet needs, advocacy, teaching, collaboration, and coordination. We serve many but delight in the uniqueness of each individual as we endeavor to promote health and wellness.

Personal Attributes of a Developmental Disabilities Nurse

- Ability to relate comfortably, confidently, and effectively with individuals with developmental disabilities
- Sincere interest in supporting individuals with developmental disabilities and in the provision of humanitarian, sophisticated, and quality care
- Ability to isolate problems and implement effective action towards their solution
- Ability to motivate change in others
- Ability to work in team situations with other professionals in various disciplines and with individuals with developmental disabilities
- A positive attitude towards individuals with developmental disabilities and their care
- Adherence to values and ethics commonly associated with professionals having access to confidential and sensitive client/consumer information
- Ability to serve all individuals without discrimination as to race, color, creed, age, sexual orientation, or abilities

Professional Certification in Developmental Disabilities Nursing

The Professional Organization for Nurses Serving Individuals with Developmental Disabilities

The Developmental Disabilities Nurses Association (D.D.N.A.) was incorporated in 1992 as a non-profit professional nursing organization founded to meet the professional needs of nurses serving individuals with developmental disabilities. Governed by a five-member Board of Directors consisting of the elected officers, The Developmental Disabilities Nurses Association represents the collective interests of its members through a national structure and regional networks. The Developmental Disabilities Nurses Association prides itself on advocating, educating, and celebrating the unique and specialized role of the nurses who serve people with developmental disabilities.

Mission Statement of the Developmental Disabilities Nurses Association

"As nurses in the specialized field of Developmental Disabilities, our mission is to continually develop our expertise to assure the highest quality of life to the people we support throughout their life span."

Become a Certified Developmental Disabilities Nurse

The Developmental Disabilities Nurses Association, in collaboration with the National League for Nursing Test Service, established a national professional certification program for achievement of the Certified Developmental Disabilities Nurse (C.D.D.N.) credential in 1995. This certification process has been developed to provide tangible recognition of professional achievement in a defined functional and clinical area of nursing-developmental disabilities. The Developmental Disabilities Nurses Association is a non-profit specialty organization that fosters high standards of ethical and professional practice through a recognized, credible credentialing program.

The Value Of National Professional Certification: Why Certify?

Certification attests to the attainment of specialized knowledge beyond the basic nursing credential. Certification serves to maintain and promote quality nursing care by providing a mechanism for nurses to demonstrate their proficiency in a nursing specialty area. It documents that special knowledge has been achieved, elevates the standards of developmental disabilities nursing practice, and provides for expanded career opportunities and advancement within the specialty of developmental disabilities nursing. Certification benefits the individual nurse, the profession of nursing, and the public.

Certification is reserved for those nurses who have met requirements for clinical or functional practice in developmental disabilities nursing, a specialized field. After meeting practice requirements, nurses take a certification examination, based on nationally recognized standards, to demonstrate their special knowledge and skills that surpass those required for licensure.

The certification examination is an objective, multiple-choice test that covers knowledge, understanding, and application of professional nursing theory and practice related to developmental disabilities. The examination blueprint was developed based on a job task analysis survey compiled by The Developmental Disabilities Nurses Association

Nurses Benefit

National professional certification is an important step for nurses. It represents the opportunity to gain recognition, visibility, and credibility. It is an accomplishment recognized by consumers, colleagues, and employers. It is a source of personal achievement that allows certified nurses to set themselves apart from their peers. Developmental disabilities nurses who become nationally certified demonstrate a commitment to the professionalism of their specialty and to the individuals they serve.

Employers Benefit

National professional certification shows that a candidate for employment possesses a core body of knowledge. It stands as a commitment to professional and ethical service. It also means that the nurse is committed to self-improvement and respect for the individuals they serve. Certified Developmental Disabilities Nurses are at work in a number of capacities: as consultants; in public agencies; in private agencies; in research facilities; group homes; sheltered workshop programs; children's hospitals; schools; institutions; and other settings. Employers find that professionally certified nurses attract clients because their credentials stand for quality, consistency, and professional service. Many regulatory surveying entities are requesting or requiring professional certification.

Consumers Benefit

National professional certification assures consumers and their families that their interests are being protected. They feel more comfortable using the services of nationally certified practitioners. Consumers and their families can trust that they are being served by a recognized professional.

The Role of the Developmental Disabilities Nurse

In addition to the variety of roles inherent in nursing, the nurse practicing in the field of developmental disabilities is responsible for additional roles in order to provide holistic and comprehensive care. It is important to remember that caring for individuals with developmental disabilities may be a complex process. Caring should be based on the framework of professional nursing that is enriched/enhanced with specific knowledge of developmental disabilities.

Developmental disability nursing roles include:

1. Clinician

- Ability to use the nursing process in caring for individuals with a developmental disability.
- Ability to make nursing diagnoses and plan for care with individuals who may have some cognitive limitations and caregivers who are not health care professionals.
- Ability to practice within established acts and guidelines.

2. Communicator

- Possess skills necessary to communicate information to the individual with a developmental disability, with caregivers, with health care professionals, and with team members.
- Ability to document information for access by authorized individuals.

3. Teacher and Counselor

- Provide information
- Identify learning needs
- Make appropriate referrals
- Problem solve
- Make decisions
- Counsel towards health promotion
- Promote wellness
- Prevent illness
- Restore health
- Facilitate coping

4. Advisor and Leader

- Plan
- Organize
- Direct
- Control means for ongoing evaluation

5. Advocate

- Protect individual
- Support individual rights

It is important to note that these roles must be implemented within the scope of nursing practice and in conjunction with each particular employer/agency. While the roles of nurses may vary among work situations, the key roles above should guide the developmental disabilities nurse in his/her care.

General Guidelines for Nurses in Community Residential Programs Supporting People with Intellectual/Developmental Disabilities were developed in the Southeast Region of Pennsylvania in 2008 to address how nursing expertise could best be utilized in the community setting. Please see Appendix.

Pennsylvania Nursing Standards and Scope of Practice

The Commonwealth of Pennsylvania Bureau of Professional and Occupational Affairs through the State Board of Nursing and the Pennsylvania Nursing Act has defined the standards and scope of practice expected to be adhered to by the developmental disabilities nurse. It is expected that the nurse who provides professional nursing services to people with developmental disabilities will do so in accordance with the appropriate parts of the Pennsylvania Nursing Practice Act, which governs their practice.

The purposes of the PA Nursing Act are:

- To protect the public from unsafe practices
- To serve as a guide to evaluate the safety and efficacy of care
- To determine when nursing practice is below the expected level of care
- To interpret standards and scope of practice for the nurse

Expectations

It is expected that all developmental disabilities nurses will use the basic nursing process (assessment, diagnosis, plan, implementation and evaluation) in their practice and that all steps of the nursing process will be documented.

The following describes application of the nursing process for developmental disabilities nurses in Pennsylvania:

Assessment

A comprehensive nursing assessment should be done at least annually prior to the development of a person's Individual Support Plan (ISP) and as necessary, as a person's health status changes.

The assessment should be amassed from objective and subjective data available to the nurse and should be based on physical examination, observations, interviews and review of written information concerning the person.

The assessment must be written and available in the person's record.

Diagnosis

The nurse analyzes the assessment data to arrive at nursing diagnoses; however, a health problem list may be used in place of nursing diagnoses to make it easier for all members of the person's team to understand the process.

Outcome Identification

The nurse identifies expected individualized outcomes. Outcomes are reasonable and measurable.

Examples of measurable outcomes:

- Will have no more than 3 seizures per month
- Will have 2 or fewer suppositories per month

Examples of non-measurable outcomes are:

- Seizures will be well controlled
- Will be free of constipation

Planning

Prior to the person's ISP meeting the nurse develops a Health Promotion Activity Plan (HPAP) that outlines interventions necessary to attain desired health outcomes for the individual. The HPAP is presented to the person's support team for their input and review. The content of the HPAP becomes part of the Individual Support Plan in the section entitled "Health Promotion" while the actual HPAP is placed in the home where it is easily accessible to all who support the person with the disability.

The plan should be written so that it is easy to understand and implement. The person(s) responsible to carry out the interventions are identified. Staff who are expected to implement the plan receive training on the plan.

Implementation

Interventions established within the HPAP should be implemented in a safe, timely and appropriate manner. Data should be collected to assess progress to desired outcomes.

Evaluation

The nurse evaluates the person's progress toward attainment of outcomes/goals. The effectiveness of interventions is assessed.

Progress data should be evaluated at least monthly and used to revise the HPAP as needed.

Revisions

The HPAP can be changed/amended at any time due to changes that may occur (signs/symptoms of the condition, interventions, and/or frequency of evaluation have changed). The HPAP will be reviewed annually at the ISP.

Developmental Disabilities Nursing Standards

Standards of practice for Developmental Disabilities Nursing have been established by the Developmental Disabilities Nurses Association (DDNA). These standards demonstrate responsibility and accountability in the profession and to the individuals served. As developmental disabilities nurses we work in very specialized and diverse environments. We assist individuals and families in achieving the highest possible level of health and wellness.

Developmental disabilities nurses are exceptional professionals who possess the knowledge base and skills to work with individuals and groups. The developmental disabilities nurses' knowledge base is diverse including such areas as health promotion, health maintenance, communication, nutrition, specialized therapy and adaptive equipment needs. They need to meet standards established by federal agencies, state licensing, and agency requirements.

Developmental Disabilities Nursing Standards are outlined according to the nursing process. Assessment, Diagnosis, Planning, Implementation and Evaluation give nurses the information that enables them to provide the best care possible to people receiving services. The Developmental Disabilities Nurses Association (DDNA) has published a formal document entitled Standards of Developmental Disabilities Nursing Practice.

American Nurses Association Code of Ethics

A code of ethics is used by professionals to police and regulate the service they offer, and frequently reflects current standards and licensing regulations. Nurses in the field of developmental disabilities nursing should adhere to the following codes from the American Nurses Association and the Pennsylvania Developmental Disabilities Nurses Network.

Code for Nurses from the American Nurses Association

1. The nurse provides services with respect for human dignity and the uniqueness of the client unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.
2. The nurse safeguards the client's rights to privacy by judiciously protecting information of a confidential nature.
3. The nurse acts to safeguard the client and the public when health care and safety are affected by the incompetent, unethical, or illegal practice of any person.
4. The nurse assumes responsibility and accountability for individual nursing judgments and actions.
5. The nurse maintains competence in nursing.
6. The nurse exercises informed judgment and uses individual competence and qualifications as criteria in seeking consultation, accepting responsibilities, and delegating nursing activities to others.
7. The nurse participates in activities that contribute to the ongoing development of the profession's body of knowledge.
8. The nurse participates in the profession's efforts to implement and improve standards of living.
9. The nurse participates in the profession's efforts to establish and maintain conditions of employment conducive to high quality nursing care.
10. The nurse participates in the profession's effort to protect the public from misinformation and misrepresentation and to maintain the integrity of nursing.
11. The nurse collaborates with members of the health professions and other citizens in promoting community and national efforts to meet the health care needs of the public.

Pennsylvania Developmental Disabilities Nurses' Network Code of Ethics

Ethical Guidelines

The nurse who specializes in developmental disabilities nursing:

- **Promotes and maintains** a safe environment which enhances the physical, emotional and spiritual well-being of the people supported by the nurse
- **Contributes significantly** to the services provided for people with developmental disabilities in a manner that conveys dignity and respect for all people with developmental disabilities
- **Recognizes and respects the rights** of all people with developmental disabilities and advocates to protect those rights
- **Maintains confidentiality** at all levels in accordance with professional standards, agency guidelines and federal law
- **Accepts responsibility and is accountable** for developing expertise in developmental disabilities nursing practice through self-development and continuing education
- **Makes a contribution** from a nursing perspective while recognizing the collaborative nature and unique role of interdisciplinary treatment teams
- **Is committed** to making contributions to developmental disabilities nursing practice through innovation and diligence
- **Collaborates** with other health professionals and the public in promoting community, national, and international efforts to meet health needs

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SECTION 5

D **ELEGATION**

Delegation of Nursing Care

What is Delegation?

Delegation is the transfer of responsibility for the performance of an activity from one individual to another while retaining accountability for the outcome. Example: the nurse, in delegating an activity to an unlicensed person, transfers the responsibility for the performance of the activity but retains professional accountability for the overall care.

“In delegating, it is the RN who uses professional judgment to determine the appropriate activities to delegate. The determination is based on the concept of protection of the public and includes consideration of the needs of the patients, the education and training of the nursing and assistive staff, the extent of supervision required, and the staff workload. Any nursing intervention that requires independent, specialized, nursing knowledge, skill or judgment cannot be delegated.” (American Nurses Association, 1992)

Questions to Ask When Considering Delegation

1. Is the task within the scope of practice of the RN?
2. Has there been an assessment of the individual's needs?
3. Is the nursing task within the knowledge, skill and ability of the nurse delegating the task?
4. Is the unlicensed assistive person competent to accept the delegation?
5. Can the task be safely performed without requiring nursing judgment?
6. Can the task be performed without repeated nursing assessments?
7. Are there appropriate resources and support available for performance of the task?
8. Is appropriate supervision available?

Regulation

The Pennsylvania State Board of Nursing has authority over the RN who delegates. It is the responsibility of the nurse to practice in accordance with the Nurse Practice Acts to ascertain whether a practice or delegation is acceptable to the professional nursing community. It is also the nurse's responsibility to exercise professional judgment in the treatment of individuals.

Prior to Delegation:

1. Assess the client for stability
2. Confirm the credentials of the unlicensed assistive person (UAP)
3. Observe the UAP performing the task to assure that the person does the task safely and accurately
4. Leave instructions for performance of the task for the UAP to use as a reference
5. Instruct the UAP that the task being taught and delegated is specific to this client only and is not transferable to other clients or taught to other care providers

Evaluation

The registered nurse should, at regular intervals, assess and evaluate the condition of the client and review the procedures and directions established during the initial delegation.

Other Resources

For further information or clarification, please see the “Delegation Decision-making Tree” by the *National Council for the State Boards of Nursing, Inc.*, or visit www.nursingworld.org for the American Nurses Association (ANA) position statements regarding delegation.

The Pennsylvania Developmental Disabilities Nurses Network (PADDNN) has published a document entitled “Guidance on Delegation” which can be accessed via their website at www.paddnn.com. The introductory statement follows:

Pennsylvania Developmental Disabilities Nurses’ Network [PADDNN] Guidance on Delegation

The framework of the developmental disability system in the Commonwealth of Pennsylvania is based on the philosophy of community integration of developmentally disabled individuals to the greatest extent possible. Central to that philosophy is that most adults are competent and that competent adults are able to manage their own healthcare needs and select their own healthcare providers. Because the population of developmentally disabled individuals has increased due to general improvements in healthcare, advances in neonatal technology, and increasing recognition of and care for genetic and congenital syndromes, greater numbers of individuals with intellectual/developmental disabilities [I/DD] are being challenged by the same problems of aging as the larger population.

Fiscal and human resources are struggling to meet the growing population and the increased needs of individuals with I/DD. A shortage of nurses throughout Pennsylvania also exists. Accordingly, care that was formerly within the exclusive aegis of the nursing professions is steadily being undertaken by nonlicensed staff, commonly known as unlicensed assistive personnel (UAP)/direct support professionals (DSPs). Tasks formerly thought of as exclusive nursing activities, such as nutritional feedings by enteral tubes, for example, are being undertaken by UAP/DSPs in growing numbers which is a concern to nurses practicing in the field of I/DD. To address this concern, the Pennsylvania Developmental Disabilities Nurses’ Network [PADDNN] convened a committee to examine the issue of assumption by UAP/DSPs of an increasingly dominant role in the healthcare of individuals with I/DD that impacts the varied roles of nurses [RN and LPNs] who care for the same individuals. The PADDNN and the Committee on Delegation recognize that the issue of nursing delegation as it applies to developmental disabilities nursing is a major concern of nurses in this field.

The Pennsylvania Department of Public Welfare (DPW), Office of Developmental Programs [ODP], provides for several different models of care for individuals with I/DD, which range from family care, supported living of adult individuals, small community homes or CLAs, and intermediate care facilities [ICF-MR]. Care is also provided at day program settings. Through the DPW and ODP, each model of care setting is governed by regulation through licensing inspection instruments.

ODP regulation of community homes is through the “Licensing Inspection Instrument For Community Homes For Individuals With Mental Retardation Regulations Chapter 6400” [6400 regulations]. The 6400 Regulations are silent on the involvement of nurses with individuals who live in community homes. Only the ICF setting has a regulatory requirement [Chapter 2400, 2900] for the provision of nursing services. There is no requirement that a provider operator of community homes employ a nurse to help manage

the care of residents in community homes. In fact, many providers of care in community homes under the 6400 Regulations throughout the Commonwealth of Pennsylvania do not employ any registered or licensed practical nurses, while a provider that operates both ICF and community homes/CLA settings may employ nurses to work in the ICF settings but not in the community homes/CLAs.

In large ICFs, where nurses are present for care management by State regulation, models of delegation may have been established where UAP/DSPs are supervised by and accountable to nurses with onsite presence. However, in small community homes (formerly CLA) settings, nurses may have a limited role, or may not be present if the provider has not chosen to employ a nurse. Where a nurse is absent or has minimal presence, a provider may manage healthcare needs of the individuals it supports with UAP/DSPs. While the majority of developmentally disabled adults live in community home settings, placement of individuals does not depend solely on the complexity of individual healthcare needs. Relatively healthy adults may live in ICF-MRs; individuals with complex medical conditions may reside in community homes [*e.g. CLAs, Family Living, Life Sharing, and Support for Independent Living Programs*] where the healthcare of residents may be managed and/or provided by UAP/DSPs. UAP/DSPs working in community homes perform a wide variety of tasks and functions whether or not the provider employs a nurse.

Moreover, where nurses, both registered nurses [RNs] and licensed practical nurses [LPNs], are employed to work with individuals living in community homes/CLAs, the contractual arrangements and job descriptions for nurses may differ significantly from provider to provider. Hours worked may vary from a few hours a week to full-time with on-call responsibilities. Job duties may range from full management of individual care, including accompaniment to all medical appointments, to limited or no contact with individual residents. Because of the special circumstances of a nurse working in the various community home settings in Pennsylvania, where the role of the nurse is controlled by the provider, the relationship of the registered nurse, licensed practical nurse, and UAP/DSPs generally lacks clarity and uniformity. The provider/employer generally controls the relationship of UAP/DSPs and nurses, and therefore controls the element of accountability from UAP/DSPs to the registered nurse.

Nursing is an outcome driven, knowledge-based, process discipline that is context dependent and requires critical thinking. Nursing cannot be reduced solely to a list of tasks. The RN's specialized education, professional judgment and discretion are essential for competent, quality nursing care.^{NCSBN, 1997} Therefore, the delegation of nursing tasks to UAP/DSPs must be designated to the RN because of the specialized skills, knowledge, critical thinking competencies and judgment required in the RN professional practice role.

Accordingly, any discussion of the rights and obligations attendant upon the I/DD nurse working in various I/DD settings must carefully distinguish between the meaning of the terms "assignment", "delegation", and "supervision". "Assignment" may mean the distribution of work to individual staff members during a given work period, a downward

or lateral transfer of both the responsibility and accountability of an activity from one individual to another, or the designation of nonprofessional healthcare tasks to an unlicensed individual trained and competent to perform them. “Assignment” does not connote the employment of nursing judgment. “Supervision” is the provision of guidance by a qualified nurse for the accomplishment of an appropriately delegated nursing task or activity with initial direction of the task or activity and periodic inspection of the actual act of accomplishing the task or activity [*DDNA Position Statement on Delegation*]. A nurse may or may not supervise depending on the specific responsibilities assigned by his/her employer.

“Delegation” as a term of act within the context of nursing practice means that a nurse transfers authority for performance of a nursing task to a competent individual, while the nurse retains accountability for the transfer. Delegation cannot be implied; it must be an intentional and deliberate act of judgment and assessment of the competency of the delegatee, the health status of the individual to whom care is being provided, and the nature of the task to be delegated. The delegating registered nurse must be competent, adequately informed, and free of controlling influences. The retention of accountability requires that the registered nurse must have the opportunity to supervise and evaluate the delegated task and the condition of the individual cared for. It should be manifestly clear that in the circumstances when a registered nurse is employed in an I/DD setting, “delegation” cannot occur when the registered nurse has neither right or opportunity to assess the competency of the delegatee, or the ability to transfer authority beyond what the employer/provider may prescribe.

Neither the Pennsylvania Board of Nursing or the ODP have issued any guidance about the nursing delegation process in general, including its effect on registered or licensed practical nurses working in I/DD care settings in this State. Therefore, the Nursing Issues Committee of the Pennsylvania Developmental Disabilities Nurses’ Network has identified the need to inform and educate all persons working in this field about the process of appropriate nursing delegation. The guidelines on the delegation of nursing presented in this document are based on recommendations of the National Council of State Boards of Nursing, the Developmental Disabilities Nurses Association, and the American Nurses Association. Delegation in Pennsylvania I/DD care settings include the following “residential” and “non-residential” programs:

Residential Programs:

- Personal Care Home Licensing (PCH) (*55 PA Code Ch. 2620*)
- Child Residential and Day Treatment Facilities (CRDTF) (*55 PA Code Ch. 3800*)
- Community Homes For Individuals with Mental Retardation (CH) (*55 PA Code Ch. 6400*)
- Family Living (FL) (*55 PA Code Ch. 6500*)
- Intermediate Care Facility for the Mentally Retarded (ICF/MR) (*55 PA Code Ch. 6600*)
- Support for Independent Living (*Not a licensed program*)

Non-residential Programs:

- Older Adult Daily Living Centers (OADLC) (*6 PA Code Ch. 11*)
- Adult Training Facilities (ATF) (55 PA Code Ch. 2380)
- Vocational Facilities (VOC) (55 PA Code Ch. 2390)
- Early Intervention – Center-based (EI) (*55 PA Code Ch. 4226*)
- Early Intervention – Home-based (EI) (*Not a licensed program*)
- Family Support Services (FSS) (55 PA Code Ch. 6350)

In order to provide safe, effective healthcare for individuals with I/DD, it is our recommendation that provider agencies in conjunction with nurses develop and implement consistent policies and procedures that actively support nurses' responsibilities, as defined in the Nurse Practice Acts and regulations of the Pennsylvania State Board of Nursing. These policies and procedures shall be cognizant of the distinction between registered nurses and licensed practical nurses. Until such time that these are developed only general guidance regarding delegation in I/DD settings can be promulgated by this committee, however, we provide the following resources in helping to understand the delegation process as it exists in the wider nursing community.

Developmental Disabilities Nurses Association Position Statement on Delegation

As developmental disabilities nurses we must work to ensure that adequate and sensitive services and flexible resources are, to the greatest extent possible,

- cost-effective
- least intrusive
- most normative
- provided by qualified, trained personnel
- meet individual needs and preferences.

The professional developmental disabilities nurse who provides care for the consumer determines if, when, what, and to whom to delegate tasks.

It is the purpose of unlicensed assistive personnel (UAPs) to enable the professional developmental disabilities nurse to provide nursing care for the consumer, and it is the nursing profession that defines and supervises the education, training, and utilization for any unlicensed assistant roles involved in providing delegated nursing tasks.

The professional developmental disabilities nurse must consider the following factors for any delegation decision:

State Nurse Practice Act and Other Applicable State/Agency Regulations

Since delegation is not defined by law or regulation in all states and is often defined differently in different states, professional nurses in each state must know the legal scope of nursing practice according to their own state's nurse practice act and any other regulations that are applicable. The differences among state nurse practice acts may be broken down according to the following questions:

- **Program Limitations** – Is nurse delegation limited to only certain programs providing home and community-based services or only institutional settings?
- **Personnel Limitations** – Who, by title, may be the delegate to whom authority to perform designated nursing tasks has been transferred?
- **Task Limitations** – Does the law identify: (a) specific tasks that can be delegated, (b) tasks that are permitted without delegation (i.e., assignment), and/or tasks that cannot be delegated at all?
- **Required Procedures for Delegation** – Are specific procedures or process standards included in the law or regulation?
- **Consumer Limitations** – Must consumers have the capacity to self-direct their care or are surrogates for consumers of impaired mental capacity permitted to oversee services?
- **Consumer Role** – What substantive or procedural rights of consumers are granted or specifically recognized? These rights could touch upon consent, or control over decisions, access to service, or rights to notice and information.
- **State Board's Position** – Has the state board responsible for nursing practice standards in your state issued a ruling or other similar recommendations regarding standards for delegation of nursing tasks to UAPs?

Standards of Nursing Practice

As nurses with a specialized area of practice, we are professionally and ethically obligated to promote and support standards of practice in our specialty. These standards define our professional accountability to the public and the individual outcomes for which we are responsible. They also provide a direction and framework for the evaluation of our practice.

Capacity of the Consumer

Capacity does not equal competency. Most consumers are capable of at least some informed decisions; some consumers may be capable of directing their own care. This capacity may vary over time and may vary across different decisions. Therefore, except for those who are most profoundly impaired, the evaluation for capacity needs to be decision-specific.

Condition/Stability of the Consumer

The professional nurse should assess the consumer's condition/stability to determine what nursing procedures could safely be performed by UAPs. Tasks should not be delegated to a UAP when the consumer's condition can no longer be classified as chronic or stable and for whom the performance of the assigned task could not be termed routine. A UAP should be assigned only minimal health-related tasks for consumers with unstable health conditions.

Complexity of the Procedure

The professional nurse may delegate to unlicensed personnel selected nursing tasks that help implement the registered nurse's directed plan of care. These nursing tasks should not require the nursing process components of assessment, planning, and evaluation during implementation. Nursing procedures that require an understanding of nursing process or nursing assessment and judgment during implementation are licensed activities. Nursing activities of health counseling, teaching, case finding and referral may not be delegated. The nurse retains the responsibility for the total process and for its outcomes in all situations in which delegation has occurred.

Abilities of the Unlicensed Personnel

The UAPs should possess skill in core areas such as:

- basic reading, writing and communications skills;
- a basic understanding of consumers' rights, including confidentiality, the right to privacy, the right to refuse care and the right to be treated with dignity;
- culturally sensitive interpersonal communications;
- role clarification;
- principles of consumer safety, including infection control and standard precautions; and feel competent that they can perform the activities.

Amount and Type of Training Required

Teaching is an essential part of delegation. To effectively train UAPs, professional nurses should possess the knowledge and specialized skills needed to perform and teach specific nursing tasks; and, based on the education and experience of the UAPs, nurses should determine the amount

and type of training required for each UAP to perform delegated nursing tasks. Nurses need to be qualified to assess care plans, perform procedures, teach individuals from a variety of backgrounds and educational levels in a variety of environments, and consider the overall context of care. The education and training of UAPs to perform delegated nursing tasks may only be performed by a professional nurse.

Amount and Type of Supervision Required

Supervision is the provision of guidance by a qualified nurse for the accomplishment of a nursing task or activity with initial direction of the task or activity and periodic inspection of the actual act of accomplishing the task or activity. It is the responsibility of the professional involved to exercise his/her judgment as to the amount and type of supervision required depending on:

- the services to be performed;
- the skill and experience of the persons involved; and
- the individual consumer nursing diagnosis(es).

Documentation

For each task delegated, the professional nurse should document the following:

- the specific task that was delegated;
- the circumstances under which the task may be performed;
- the person(s) to whom and for whom the task was delegated;
- the appropriate direction and communication needed;
- the amount and type of supervision required; and
- the outcome of the delegated task.

Liability Issues

A violation of the scope of duty under a nurse practice act is not enough in itself to create liability. If no one is hurt, there is no liability. Or if someone is hurt, but it was a result of something other than the nurse's violation of duty, there is no liability.

To be liable for any injuries to consumers caused by the acts of a nurse-delegate, negligence would have to be proven. Negligence requires four elements generally:

1. the party allegedly at fault must have had a duty – an ascertainable standard of care;
2. the party must have breached that duty;
3. there must be an injury to another; and
4. the violation of duty must be the proximate cause of that injury.

If any one of these elements is missing, there is no liability. There may still be a lawsuit, because almost anyone can assert negligence in a personal injury suit, but it will not be successful unless all four elements are proven by a preponderance of evidence.

The nurse remains ultimately responsible for the care provided, but the scope of this responsibility should be made clear because being responsible for the task of delegation is not the same as being responsible for the actual performance of the delegated task.

REFERENCES

- American Nurses Association. (1992). Position Statement: Registered Nurse Utilization of Unlicensed Assistive Personnel. Washington, DC: Author.
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- Pennsylvania Developmental Disabilities Nurses' Network. (2007). Guidance on Delegation. Philadelphia, PA: Author.
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SECTION 6

NURSING RESPONSIBILITIES

Nursing Documentation

A person's health care record provides legal proof of the nature and quality of care that the person receives.

A well-documented health care record:

- Records all pertinent events
- Documents the care given
- Demonstrates the results of interventions
- Assists in the planning and coordination of care by various entities (staff, nursing, ancillary consultants, etc.)
- Adheres to standards, rules, regulations and laws of nursing practice

Nursing documentation is generally found in progress notes or communication logs, which are usually done in the narrative format and include entries from direct care staff, home managers, the nurse, and other health care professionals. As a legal document, the date and time of entry must be recorded along with the full signature of the author. Do not use whiteout, blacken, or obliterate entries. The nurse should use vocabulary that can be understood by all. Avoid abbreviations, acronyms or double documentation whenever possible.

There is no specific requirement for the frequency of entries. Rather, they are made as health issues arise. Most importantly, when someone identifies a health problem, the progress notes need to include interventions and results.

It is often the RN who follows up on all progress notes made by direct care staff. This follow up can include an assessment of the problem, interventions used or planned and results.

It is suggested that progress note entries be available in the current record for the past six months. In addition to the progress notes, data may be recorded on various flow sheets (e.g., vital signs, weights, menses, seizures, telephone communication notes, etc.)

Nursing Orders

Within a nurse's scope of practice is the ability of the licensed nurse to write nursing orders based upon the nurse's assessment and plan of care, for example:

- Clarifying a physician's order, such as "Antibiotic 500 mg bid" can be clarified to read: "Antibiotic: take two 250 mg caps at 8am and 8 pm"
- Preventative measures, such as increasing fluids, providing sunscreen or measuring input and output
- Physical management issues such as repositioning every two hours or elevation of an edematous limb

Group homes are residential sites that require a signed physician's order for any medication, prescription or non-prescription treatments and diets. It may be helpful to obtain as needed (PRN) physician orders for over the counter medications for expected interventions, such as skin treatments (antibacterial cream for skin abrasions) or pain/fever medications.

As per the Pennsylvania State Board of Nursing ruling posted December 20, 2003, Licensed Practical Nurses (LPNs) are able to take verbal orders from a physician. The Registered Nurse (RN) and LPN should be aware of the responsibility inherent in receiving verbal orders as outlined in the Professional Nurse Law and Practical Nurse Law issued by the Pennsylvania State Board of Nursing. The RN and LPN should also be aware of and follow their agency policy and procedure regarding verbal orders. The physician's signature for the verbal order should be obtained in a timely fashion or as per agency policy when the nurse writes an order.

First aid measures may be implemented as per agency policy; however it is recommended that a physician follow up occur as soon as possible if further intervention is needed.

Nurses may find conflict within the residential services system over nursing orders. Group homes are usually structured so that the house manager, not the nurse, supervises the direct care staff. The nurse needs to consider the Developmental Disability system's values of integration, inclusion and empowerment of the person being served when requesting or implementing health interventions.

Nurses may also find conflict when the scopes of the practices of various health professionals overlap. Clear communication with all disciplines is vital in protecting the health of the person residing in the home. Nurses should discuss with their employer or contractor how these conflicts should be handled. (e.g. who should decide when someone should stay home from work when sick).

Nursing Reviews/Assessments

The nurse's focuses are health promotion, health maintenance, health restoration and end of life care. The nursing process of assessing, diagnosing, planning, implementing and evaluating must be utilized. It is important that the following be assessed upon initial interview and placement.

- Developmental assessment/history
- Cultural assessment/history
- Spiritual assessment
- Nutritional assessment
- Physical assessment
- General assessment and vital signs

There are many different assessment instruments available to gather information and develop health care plans. In the field of developmental disabilities a plan of care is extremely important to give direction to the individual and anyone who provides care. A baseline physical assessment of all the body systems needs to be done and the plan of care should be developed. A sample Community Health Review and Nursing Assessment are provided in the Appendix.

The plan of care must be individualized, using non-medical terminology. If it is necessary to use medical terms they should be defined so that everyone involved is able to understand. Training must be provided by the nurse to all parties involved with plan implementation. The plan should be updated whenever there is a change in status, and must be reviewed periodically and at least annually.

Health Promotion Activity Planning

With the initiation of a uniform statewide Individual Support Plan (ISP) through the Home and Community Services Information System (HCSIS), the Health Promotion Activity Plan (HPAP) has become an integral part of the planning process in the southeast region of Pennsylvania. The HPAP was developed to benefit Health Promotion efforts and serve as a guide for supports coordinators to provide specific health information necessary for the ISP.

People with a developmental disability will be better supported with a Health Promotion Activity Plan, which differs from a nursing care plan in that:

1. The focus is not on nursing diagnoses but on the particular medical condition
2. Interventions are not necessarily those which would be performed by a nurse but by caregivers
3. Rather than a formal plan, it should be an easy to read and understand guide for care

The main goal of having a plan is to provide consistent, organized, and beneficial care to each individual. The Health Promotion Activity Plan offers caregivers easy access to information regarding health conditions as well as a plan or guidelines for care. Because multiple caregivers are usually responsible for supporting an individual, this plan provides a consistent method for care regardless of the caregiver or the time of day. It also shares some guidelines to evaluate the effectiveness of the interventions and whether they should be changed to meet the needs of the individual more fully.

There is no one way to create a plan, and creativity is encouraged. The intent is for it to be easy to understand, follow, and evaluate. The long-term outcome should be that caregivers are able to provide optimal care within their scope of duties, thus enhancing the nurse's care.

A template or guide for the Health Promotion Activity Plan is provided in the Appendix. It has been developed to prompt the writer to provide complete information. A sample Health Promotion Activity Plan for the diagnosis of Seizure Disorder is also provided in the Appendix.

Sample Health Promotion Activity Plans are available on the PCHC website at www.pchc.org. Click on Health Topics for a directory of HPAPs.

Communication

Communication for Developmental Disabilities Nurses

In order for the developmental disabilities nurse to provide the most comprehensive and effective care to individuals, it is imperative that they utilize good communication skills. This need for effective communication must begin with the individuals being served. Once a relationship has been established with each individual, the nurse can assume an important role in facilitating communication between the person supported and members of his/her team. In addition to other medical professionals such as physicians and therapists, the team may include family members, advocates, supports coordinators, behaviorists, direct care staff, and other agency personnel.

The following guidelines offer a standard of communication that hopefully will help other members of the team in adopting the same standards.

Preparation for physician visits:

- Prior to the appointment, the individual should be prepared for what to expect, what is likely to happen, who will be there, how they will be supported, and a list should be made of the individual's questions/concerns for the doctor.
- The person who accompanies the individual should be familiar with the person, be willing and able to encourage and support him/her, and be ready to ask and answer questions for the individual if he/she is unable.
- The person accompanying the individual to the appointment should have a written list of questions for the doctor and be prepared to record the answers.
- The accompanying person should also have a summary of information to present to the physician.

The summary of information should include:

- A clear description of the problem or reason for the visit, including any changes the individual has experienced (sleep, appetite, mood, behavior, etc.)
- When the problem began, along with any suspected or known precipitating factors
- A comprehensive family, social, developmental, psychiatric, medical, and surgical history
- A list of current medical diagnoses, treatments, and medications (including over the counter medications)
- A copy of the most recent lab results as well as any other pertinent ones

Upon leaving the physician's office, the accompanying staff should have:

- A written diagnosis by the physician
- A written treatment plan including any ordered medications, labs, other tests, and recommended consultations, including time frames
- Answers to all questions, and a clear understanding of the treatment plan
- Recommendations for a follow-up appointment if needed
- When to call or return prior to the next scheduled appointment if needed

Standards of Communication for Behavioral Health Consultants

Behavioral health consultants specialize in helping to determine how an individual's behavior has an impact on his/her adjustment to their living situation. They then create a plan to maximize a positive lifestyle for each individual. Communication among the behavioral consultant and the individual, staff, family, case manager, and support persons is imperative to the creation of a supportive and community friendly environment for the individual.

The following list of expectations sets the standard for the behavioral health consultant working with individuals with mental retardation.

1. Functional Assessment and Decision to Intervene

"Behavioral intervention may only be provided in the context of an overall individualized plan which focuses on the enhancement of the quality of life and maintains a respect for individual choices, dignity, and rights"(Department of Behavioral Health/Mental Retardation Services, 1997).

"When an individual's behavior interferes with his/her personal progress, the individual's planning team may need to consider planned interventions" (Department of Behavioral Health/Mental Retardation Services, 1997).

2. Observing and Recording Behavior

The behavioral consultant will use appropriate procedures to determine how to observe and record objective data for different types of behavioral health issues. The behavioral consultant will describe the behavior or psychiatric symptoms in observable and measurable terms.

3. Developing Behavioral Procedures

Based on the findings of the functional assessment, information from the individual, his/her support team and family, and any other involved professionals, the behavioral health consultant shall develop appropriate approaches to address the presenting behaviors. Such approaches should be in keeping with the Philadelphia Behavior Intervention Policy, and should specify methods and frequency of data collection as well as the goals and objectives of such a plan.

The behavioral health consultant should review the collected data at least quarterly (every 90 days) to determine the efficacy of the behavior plan and/or prescribed medications.

Monitoring, Recording, Displaying, and Interpreting Data

The behavioral consultant will develop and use appropriate data displays to describe and summarize different types of behavioral data. Summary reports should also include a narrative description of the data provided with hypotheses about the efficacy of the behavior plan and other interventions. Summary reports will be provided every 90 days. The behavioral health consultant will link the targeted behaviors to the data that is collected in order to monitor the impact of the interventions.

4. Staff Training

One of the most critical functions of the behavioral consultant is to provide training to the individual, family members, and support staff about the behavior plan, including data collection needed for evaluation, and any planned interventions.

5. Informed Consent

The behavioral health consultant will ensure that the individual and his/her family or guardian is presented with all relevant information concerning the behavior plan and any relevant behavioral interventions. These will include data collection, intervention techniques, the rationale for any restrictive measures, planned interventions, and the use of any psychotropic medications if needed. It is only after this information is provided, and any questions answered, that informed consent may be obtained.

6. Team Participation

As part of the individual's support team, the behavioral consultant communicates regularly with other members of the team regarding emerging behavior problems, and any and all data that is being collected to assess the individual's progress toward his/her goal and current behavior interventions. The behavioral health consultant will communicate with the individual's prescribing physician if the individual is using medication to treat a psychiatric condition. Communication should be in the form of written reports, notes, phone conversations, team meetings, and face to face meetings with the prescribing physician.

Standards of Communication for Physicians Prescribing Psychotropic Medications

1. Psychiatric Assessment and Decision to Intervene

A referral initiated by the individual, his/her family, or an appropriate team member for psychiatric treatment is made to a psychiatrist (or other prescribing physician) for evaluation and possible treatment.

2. Initiation of Psychiatric Treatment

"The use of a medication must be based on a treatment plan developed by the prescribing physician in consultation with the team and in conjunction with the behavioral intervention plan when indicated" (Department of Behavioral Health/Mental Retardation Services, 1997).

The prescribing physician is expected to identify and document any psychiatric diagnoses using the DSM-IV terminology and numbering, and include an objective description of the symptoms for which treatment is being conducted. "Mental Retardation" is not an acceptable symptom or diagnosis, target behavior, or rationale for treatment with a psychotropic medication" (Department of Behavioral Health/Mental Retardation Services, 1997).

3. Monitoring and Evaluation of Treatment and Follow Up

At least every 90 days the prescribing physician will review the efficacy of the medication and treatment plan and complete a 90-day team review of psychotropic medication form.

4. Staff Training

The prescribing physician will be expected to detail for the accompanying staff, the expected effects of the medications, risks and benefits, and possible side effects. The physician will indicate which of these would require immediate medical attention. The information should be documented in written and oral forms. This information is required by the Commonwealth of Pennsylvania 6400 regulations for community residential homes and should be documented on the appropriate medical visit forms.

5. Consent

The prescribing physician will ensure that the individual, their family member, or guardian is presented with the relevant information concerning the medications prescribed, their risks and benefits, possible side effects and expected outcomes. Consent should then be obtained for psychotropic medications.

6. Team Participation

"The physician is encouraged to serve as a member of and expert consultant to the individual's planning team. The physician should maintain communication with the team through the family or staff who accompany the individual on office visits and through written documentation and telephone contacts with other members of the team, particularly the behavioral health specialist. The prescribing physician will discuss psychotropic medications and the need for their use with the team. The physician should provide the team with his/her recommendations and plan at the annual ISP meeting" (Department of Behavioral Health/Mental Retardation Services, 1997).

Working with Allied Health Professionals

The nurse in the community works closely with consultants and other healthcare providers. Often the determining factor of the need to see a consultant is a result of the nurse's assessment.

Allied health professionals may have a private contract with the agency, and in addition, services can be sought through the referral process of an MCO or other health insurance.

Once the need for a consultant has been established, the representative from the agency contacts the consultant and an appointment is made. If the appointment is made using the MCO system, a physician's order as well as a referral form is required. If the nurse is unavailable for the appointment, it is very important that the person attending with the individual is updated on his/her condition, with relevant information and facts about the condition as well as questions for the allied health professional. This will save the nurse a phone call to the physician for clarification and questions regarding the appointment.

Some recommendations from an allied health professional may require a physician's order before they can be implemented.

The following list describes some allied health professionals:

Physical Therapist

- Assesses body movements and posture
- Provides therapy or assist in training the individual and others in proper positioning, range of motion and proper body mechanics to maximize mobility and flexibility
- Determines the need for and design of adaptive equipment

Occupational Therapist

- Assess overall motor skills needed to carry out activities of daily living (e.g. hand to mouth and grasp/release patterns necessary for eating)
- Determine adaptive equipment needs
- Assess body positioning and physical endurance
- Promote cognitive and socialization skills around social eating
- Teach others to facilitate appropriate hand to mouth patterns, use of adaptive equipment and proper body mechanics
- Depending on their training, they may assess swallowing function
- Depending on training, they may assess and implement sensory integration strategies

Registered Dietician

- Assesses and monitors nutritional needs, adequacy of nutrient intake and food preferences and tolerances
- Screens for history of weight loss/gain
- Ensures that proper consistency, temperature and food choices are selected, and that adequate nutrition is provided. This may involve recommendations regarding use of nutritional supplements
- Assists with menu planning

Speech-Language Pathologist

Oral-motor skills and swallowing status:

- Assesses and performs ongoing determination of oral-motor function and swallowing status
- Recommends, assists and interprets results of videofluoroscopy studies when indicated
- Works with other professionals to determine the appropriate eating method
- Recommends diet consistency and degree of supervision required. (Remember that a physician's order is needed to permanently change the texture).
- Recommends aspiration precautions as indicated
- Trains individuals and teams in compensatory swallowing techniques

Language and Communication:

- Evaluates language and communications skills
- Assesses language comprehension and overall responsiveness
- Develops and manages exercises for speech and communication
- Develops, recommends, implements, and teaches the use of alternative communication devices
- Develops visual communication systems

Respiratory Therapy

- Assesses and monitors pulmonary status
- Assists in management of oxygen use and in other respiratory treatment techniques
- Provides consultation on choices of tracheostomy tubes
- Makes recommendations for the removal of tracheostomy tubes

Training Requirements

As nurses we are required to perform our duties in the least restrictive, holistic fashion. We must follow our state's Nurse Practice Act and abide by the specifications described therein.

The Occupational Safety and Health Administration (OSHA), Office of Developmental Programs (ODP) regulations and agency requirements may require the developmental disability nurse to complete mandatory trainings. These trainings include, but are not limited to:

- Fire Safety
- Restraint Protocol/Crisis Intervention
- Evacuation Procedures
- Medication Administration
- First Aid
- Cardiopulmonary Resuscitation

As licensed nurses it may seem that previous training in medication administration and first aid is sufficient, however, ODP licensing requirements require that all personnel working in programs regulated by ODP attend these trainings.

SAMPLE
Health Maintenance Tracking Form

Name of Individual: _____
 Date of Birth: _____

Form Completed On: _____
 By: _____

Evaluation/Procedure	Discipline	Frequency*	Date Completed	Date Due	Comments
Physical Exam	PCP	Annual	1/15/05	1/15/06	
Vision Screening	PCP	Annual	1/15/05	1/15/06	PCP may want further evaluation and will refer to ophthalmology
Hearing Screening	PCP	Annual	1/15/05	1/15/06	PCP may want further evaluation and will refer to ENT or audiology
Gynecology Evaluation	GYN	Annual	3/15/05	3/15/06	
PAP Test	GYN	Annual	3/15/05	3/15/06	
Mammogram	Radiology	Annual	4/15/05	4/15/06	Physician wants extra mammogram done in six months (10/15/05) instead of usual annual mammogram
Prostate Exam	PCP/Urologist	Annual (over 40 years)	1/15/05	1/15/06	
PSA Test	PCP/Urologist	As recommended	1/15/05	Per physician	
Hepatitis B Screening	PCP	As recommended	7/8/02	Per physician	No virus; antibody positive after receiving vaccine series (indicates immune status)
Hepatitis B Vaccination	PCP	As recommended	1/4/02, 6/4/02, 7/4/02	Per physician	
Tetanus	PCP	Every ten years	8/15/02	8/15/12	
TB Test (Mantoux)	PCP	Every two years	1/15/05	1/15/07	

*Please note that the frequencies listed in this example are based on general health screening recommendations; frequency may vary among persons because of age, sex, other health conditions, etc. This should be individualized according to need and licensing requirements.

Developmental Disabilities: Physical and Behavioral Health Conditions

Depending on the etiology of an individual's developmental disability, he/she may be more susceptible to a myriad of co-existing medical and/or mental health conditions.

Some studies have found levels of mental disorders in individuals with developmental disabilities to occur at rates of up to 70%. It has been theorized that these high levels of concurrent mental health issues are related to the "psychological vulnerability" (Virginia Commission on Youth, Mental Retardation).. Some examples include:

- Pervasive Developmental Disorder (PDD)
- Attention Deficit Disorder (ADD)/ Attention Deficit Hyperactivity Disorder/ (ADHD)
- Mood disorders (e.g. depression)
- Anxiety disorders
- Schizophrenia
- Post Traumatic Stress Disorder (PTSD)
- Obsessive-Compulsive Disorder (OCD)

Individuals with developmental disabilities are at risk of having the same medical conditions as those in the general population. However, many of these conditions are seen in much higher numbers in some members of this group. Some examples include:

- Seizure disorders
- Motor dysfunction (e.g. Cerebral Palsy)
- Visual impairment
- Hearing impairment
- Swallowing difficulties (Dysphagia)
- Cardiac problems
- Gastrointestinal problems (GERD, constipation)
- Musculoskeletal problems
- Dental problems
- Nail fungus

Other factors, which may contribute to poorer medical outcomes for this group include:

- Symptoms of a specific condition may present differently in disabled individuals than in those without disabilities
- Inability of some individuals to recognize discomfort, pain, or changes in physical functioning
- Inability of some individuals to communicate discomfort, pain, or changes in physical functioning
- Frequent lack of medically qualified caregivers serving this population
- Lack of physicians interested in, or trained to work with, individuals with developmental disabilities

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SECTION 7

BEHAVIORAL HEALTH

Psychotropic Medication Protocols

Psychotropic medications are prescribed to stabilize or improve target symptoms of a behavioral health diagnosis. When a person receives psychotropic medications for a psychiatric diagnosis, these drugs must be prescribed by a physician and must be identified in the person's Individual Support Plan (ISP) and on the Team Review of Psychotropic Medication form where applicable. The person's Individual Support Plan and Team Review Form need to identify each medication by name as well as the corresponding diagnosis associated with each medication, associated target symptom, and desired outcome or goal of treatment.

The following are best practice considerations that should be observed when psychotropic medications are used:

- Psychotropic drugs should not be used for the convenience of caregivers, as a substitute for a meaningful behavior plan, or in excessive amounts that interfere with the individual's quality of life.
- The use of a psychotropic medication should be based on a psychiatric diagnosis resulting from a review of targeted behaviors and symptoms. This does not mean that a drug cannot be changed, as long as the medication appropriately addresses the diagnosis.
- As with medical treatment, informed consent should be obtained from the person, the person's legal guardian or health care guardian if available, before initiation of a psychotropic drug. In addition, any regulatory bodies within the agency should review the use of psychotropic medication.
- Each person must be monitored for medication effectiveness by the support team. Monitoring must involve targeted behaviors as specified in the ISP and Team Review form. Measurements, charts and documentation must occur on an ongoing and consistent basis.
- Each person must be monitored for side effects regularly, based on physical assessment, caregiver's reports and information from the individual. Frequency of monitoring depends on individual circumstances and can vary from person to person.
- If a psychotropic medication is used that has the potential of causing tardive dyskinesia, screening should be completed every six months (see sample of abnormal involuntary movement scale [AIMS] test). This includes a baseline assessment when starting a psychotropic medication as well as withdrawal tardive dyskinesia. The physician or nurse may complete this monitoring.

- All psychotropic drugs must be reviewed regularly and systematically at least every 90 days, by the prescriber, with input from the team to determine the need for continued use at the lowest possible dose. There should be a plan for medication reduction.
- Advocate for keeping the drug regimen as simple as possible in order to enhance desired outcomes and minimize side effects. Avoid frequent drug and dose changes, as drugs can take varying lengths of time to work. Avoid drug changes in a reactive manner, to address short-term behavior problems, fluctuations in behavior or caregiver's frustrations.
- There should be staff training regarding signs and symptoms of mental illness, extra-pyramidal symptoms, tardive dyskinesia, medications and their side effects. Each agency should have a procedure for reporting the above-mentioned items.

Behavioral Health: Team Review of Psychotropic Medication Form Overview

This form was developed by a group of people consisting of psychiatrists, psychologists, behavioral specialists, supports coordinators, and residential staff. It is considered to represent emerging practices for positive outcomes and provides a communication basis for all members of the team. The Behavioral Health: Team Review of Psychotropic Medication Form is mandatory for all Pennhurst class members registered in Philadelphia and may be mandated by other administrative entities in Southeastern Pennsylvania.

Part One: Health Services Report

This section is to be completed by agency personnel (nurse, program manager, etc.) and reviewed by the agency nurse prior to and after the psychiatric appointment. The agency nurse should sign after the final review.

Demographic information is followed by current medications. All current medications should be listed (even non-psychiatric medications). The “Reason for Administration” for each medication should indicate a specific diagnosis.

Diagnostic information follows medication allergies. AXIS I refers to any mental health diagnosis (i.e., bipolar disorder, depression). Each diagnosis in AXIS I should be taken from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, with corroborating, documented, targeted behavioral symptoms. AXIS II refers to the level of mental retardation (i.e., mild, moderate) and to any personality disorders (i.e., borderline, histrionic). AXIS III refers to any medical diagnosis (i.e., hypothyroidism, diabetes). Axis IV refers to environmental and social stressors. AXIS V is a global assessment of ability to function.

Tardive dyskinesia screening is required every 6 months and must be documented on this sheet.

“Current health status/medical issues of note” refers to documentation of any health-related sign or symptom that has occurred in the past 90 days. Add comments or diagnostic testing with results if appropriate.

The signatures of the person completing the form and that of the agency nurse are required.

Part Two: Behavior Support Treatment Report

This section is to be completed by a monitoring team member such as a behavioral specialist, qualified mental retardation professional (QMRP), program specialist or family member.

The level of restrictiveness is required for persons registered in Philadelphia County. It is defined in the Behavioral Intervention Policy and should be available in each agency’s policy and procedure manual. Please see Appendix for Philadelphia County Behavioral Intervention Policy.

All targeted symptoms of mental illness being tracked are to be listed as well as any change in symptoms. The targeted behaviors on page two of the form should be the same as targeted symptoms on page one.

The “Summary Since Last Psychotropic Med Review” should be completed, indicating any change in the list of medical and/or behavioral symptoms listed. Specific description of any changes noted should be documented.

Current status as well as any comments regarding previous issues should be documented.

Form should be dated and signed once the Team Review of Psychotropic Medication form has been reviewed for accuracy. There is an understanding that all members of the team review the document prior to attending the psychiatric visit as well as after the appointment.

Part Three: Physician’s Report

The physician must document whether diagnoses and targeted symptoms remain the same or if changed, what the new target symptoms and goals of treatment are for the person. The physician should also document any new diagnoses and progress since the last review. There should be a medication reduction plan in place.

The physician must document answers to questions regarding psychotropic medication use and tardive dyskinesia screening.

Any medication changes or lab/diagnostic testing must be documented as ordered.

The physician and staff person accompanying the individual must sign the form.

All Team Review of Psychotropic Medication forms for Pennhurst class individuals must be forwarded to Philadelphia Coordinated Health Care.

BEHAVIORAL HEALTH: TEAM REVIEW OF PSYCHOTROPIC MEDICATION

PART TWO: BEHAVIOR SUPPORT TREATMENT REPORT

(To be completed by monitoring team member [behavior specialist, QMRP, program specialist, family member] prior to review.)

INDIVIDUAL:	DATE OF PSYCHOTROPIC MED REVIEW:
--------------------	---

LEVEL OF RESTRICTIVENESS PER BEHAVIOR INTERVENTION POLICY**

LEVEL I
 LEVEL II
 LEVEL III
 NOT APPLICABLE (Not registered with Phila.)

***This is only for individuals funded by Philadelphia County, see Philadelphia Behavior Intervention Policy for details*

TARGET SYMPTOMS BEING DOCUMENTED

*Include **BEHAVIORAL DESCRIPTIONS** of Target Symptoms for each mental health diagnosis listed on Axis I on Part 1 of this form. Behavioral descriptions must be **specific to the individual**. For each target symptom, **fill in the number of occurrences for the past 6 months**. Additional charts/graphs may be attached. **Add comments wherever possible.***

Target Symptoms (from Part 1) BEHAVIORAL DESCRIPTION <i>(MUST MATCH those listed on Part 1)</i>	Monthly Data (past 6 months) <small>Fill in month and frequency of each Target Symptom</small>	Comments								
1)	<table border="1" style="width: 100%; border-collapse: collapse; height: 20px;"> <tr> <td style="width: 12.5%;"></td> </tr> </table>									
2)	<table border="1" style="width: 100%; border-collapse: collapse; height: 20px;"> <tr> <td style="width: 12.5%;"></td> </tr> </table>									
3)	<table border="1" style="width: 100%; border-collapse: collapse; height: 20px;"> <tr> <td style="width: 12.5%;"></td> </tr> </table>									
4)	<table border="1" style="width: 100%; border-collapse: collapse; height: 20px;"> <tr> <td style="width: 12.5%;"></td> </tr> </table>									

ADDITIONAL CONCERNS SINCE LAST REVIEW

Check any symptoms or environmental changes *not being documented above* that have appeared since the last review (clarify in Additional Comments section below)

<input type="checkbox"/> Activity Level (increased or decreased)	<input type="checkbox"/> Obsessive-Compulsive Behavior	<input type="checkbox"/> Unusual Body Movements (e.g., tremors)
<input type="checkbox"/> Anxiety	<input type="checkbox"/> Sleep Changes	<input type="checkbox"/> Other (Specify):
<input type="checkbox"/> Appetite (increased or decreased)	<input type="checkbox"/> Suicidal ideation/behavior	<input type="checkbox"/> None
<input type="checkbox"/> Change in Mood	<input type="checkbox"/> Environmental Issues	<input type="checkbox"/> Psychotic Symptoms

Check if there were incidents this review period related to the individual's behavioral health diagnosis or target symptoms, and fill in the number of incidents:

ER Visits _____
 Psychiatric hospitalizations _____
 Restraints _____

ADDITIONAL COMMENTS

Signature(s) indicate that prior psychotropic medication review reports were reviewed in preparing this report. *This form can be completed for any appointment but psychotropic medications **MUST BE REVIEWED EVERY 90 DAYS MINIMUM.***

SUMMARY COMPLETED BY:	Date form completed:
Name:	Date reviewed with team:
Role:	Date reviewed w/prescribing physician:
Signature:	

BEHAVIORAL HEALTH: TEAM REVIEW OF PSYCHOTROPIC MEDICATION

PART THREE: PHYSICIAN'S REPORT *(To be completed by physician prescribing psychotropic medication)*

INDIVIDUAL:			
DATE OF PRESENT PSYCHOTROPIC MED REVIEW:		DATE OF NEXT PSYCHOTROPIC MED REVIEW:	
PHYSICIAN'S AGREEMENT WITH CURRENT DIAGNOSES AND TARGET SYMPTOMS: (see Page 1 and Page 2) Do the diagnosis(es) in Part 1 and the target symptoms in Part 2 remain as indicated on Part 1: <i>Health Services Report</i> and Part 2: <i>Behavior Support Treatment Report</i> ? <input type="checkbox"/> Yes <input type="checkbox"/> No If NO, please change to:			
TREATMENT GOALS (Regarding Target Symptoms listed on Parts 1 and 2):		PROGRESS TOWARD GOALS:	
◆ Psychotropic medications are necessary?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Psychotropic medication dosages are within usual range?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Number of drugs conforms to accepted standards?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Are medication side-effects present? <i>(e.g. sedation, ataxia, dyscrasia)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Screening test performed (e.g. AIMS)?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Symptoms of T.D. or other E.P.S.?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
◆ Medication reduction plan considered?	<input type="checkbox"/> Yes <input type="checkbox"/> No		
PHYSICIAN'S ORDERS			
MEDICATION CHANGE: <input type="checkbox"/> No <input type="checkbox"/> Yes <i>(provide information below)</i>			
NEW MEDICATION <i>(List medication, dosage & frequency)</i>			REASON FOR NEW MEDICATION
Medication	dosage	frequency	Medication Education Provided? <input type="checkbox"/> Yes <input type="checkbox"/> No
1)			
2)			
3)			
MEDICATION CHANGE <i>(List med., dosage & frequency)</i>			REASON FOR MEDICATION CHANGE
Medication	dosage	frequency	Medication Education Provided? <input type="checkbox"/> Yes <input type="checkbox"/> No
1)			
2)			
3)			
MEDICATION DISCONTINUED <i>(List med., dosage & frequency)</i>			REASON FOR MEDICATION DISCONTINUATION
Medication	dosage	frequency	Medication Education Provided? <input type="checkbox"/> Yes <input type="checkbox"/> No
1)			
2)			
3)			
LAB STUDIES, DIAGNOSTIC TESTS AND FREQUENCIES: Metabolic screening done? <input type="checkbox"/> Yes <input type="checkbox"/> No Date: _____			
COMMENTS/CHANGES/REASONS/AREAS OF CONCERN:			
My signature below indicates that I have reviewed the Health Services and Behavior Support Treatment Reports. I have reviewed my recommendations, as well as the consequences to the individual for not following my recommendations with all parties attending this review. [This form can be completed for any appointment but psychotropic medications MUST BE REVIEWED EVERY 90 DAYS MINIMUM.]			
Physician's Printed Name, Signature and Date:			Clinician: Signature, Title and Date:
Consumer's Consent for Psychotropic Medication: Signature and Date:			
Accompanying Person's Printed Name, Signature and Date:			

Extrapyramidal Symptoms and Tardive Dyskinesia

Psychotropic medications are still given to large numbers of people with developmental disabilities (DD) and many people receive more than one psychotropic medication. Some estimates range as high as 77% for institutionalized individuals with many receiving more than one psychotropic medication (Hill, S.C. and Tyrer, S.P., 2000, pp.16-21). For this reason, many individuals may be at risk for developing extrapyramidal symptoms (EPS). Though many classifications of psychotropic medications may be used, the most common are neuroleptic agents, such as antipsychotic or antianxiety agents. Neuroleptic medications may also be used in the treatment of some neurological or gastrointestinal disorders.

Extrapyramidal symptoms are a potential neurological side effect of neuroleptic medications. They may occur early in treatment with neuroleptics, but generally resolve quickly. Tardive (late) dyskinesia (movement), is a type of extrapyramidal symptom, which occurs after long-term use of neuroleptic medication (late onset of movement.) It is characterized by potentially irreversible, involuntary, repetitive movements in the muscles of the limbs, trunk, and face. Tardive dyskinesia occurs in approximately 15% of those people taking neuroleptics within just three years (Tardive Dyskinesia), and symptoms increase in relation to the length of time a medication is taken, as well as the dosage.

While the majority of the cases of Tardive Dyskinesia are mild, severe cases may involve problems such as difficulty swallowing, respiratory problems, speech problems, difficulty or inability to stand, or cosmetic disfiguration. The course of tardive dyskinesia is unpredictable; symptoms may wax and wane, occur in different areas of the body at different times, and be exacerbated by stress. After medication reduction or discontinuation, or over time, symptoms may improve or even disappear. However, it has been estimated that in 10 – 20% of people taking neuroleptics, when the medication is reduced or discontinued, a condition called Withdrawal Emergent (Tardive) Dyskinesia may occur (Drug Induced Movement Disorders). In this condition, symptoms emerge which may not have been present, or symptoms which were previously present may be temporarily exacerbated. This is most likely to occur after an abrupt withdrawal of medication. Symptoms may resolve without intervention over several weeks, or benzodiazepines may be effective if there is an anxiety component to the symptoms. Covert Dyskinesia is a form of Tardive Dyskinesia where symptoms of the latter have been masked by the administration of psychotropic medications, and went unrecognized prior to medication withdrawal.

People at higher risk for Tardive Dyskinesia include:

- Females
- Older people
- Substance abusers
- People with epilepsy
- People with diabetes
- People with mood disorders
- People who take high doses of neuroleptics

- People who use older classes of neuroleptics
- People who are on long term treatment with neuroleptics
- People who are being treated with multiple neuroleptic medications
- People who receive neuroleptics via injection administration
- People with underlying “soft neurological” factors or mental retardation

Regular monitoring for signs of Tardive Dyskinesia should be done every 6 months at the minimum, and preferably every 3 months, by a physician or a nurse, and may be done using scales such as the:

- Abnormal Involuntary Movement Scale (AIMS) – *sample included in this section*
- Dyskinesia Identification System: Condensed User Scale (DISCUS) – *sample included in this section*

There is no standard treatment for Tardive Dyskinesia, but treatments may include:

- Replacing the neuroleptic medication with a non-neuroleptic
- Gradually weaning the medication to the lowest possible dose
- Giving medications to suppress Tardive Dyskinesia such as:
 - Calcium channel blockers (e.g., Nifedipine)
 - Adrenergic antagonists (e.g., Hytrin)
 - Antidyskinetics (e.g., Cogentin)
 - Vitamin E

Recognition of Movement Disorders

(Anderson & Freeman, 2004, p.14-26)

Localized Symptoms	
Body area	Associated movement symptoms
Neck/spine symptoms	<p>Muscle spasms of the neck (cervical) which pull the head to the side (torticollis), forward and down (antecollis), or up (retrocollis) are often painful. An extreme bending at the waist is rare (Pisa Syndrome or pleurothotonus). The most extreme form of back arching can bring the entire body off the bed except the back of the head and the heels (opisthotonus). Pelvic rocking or gyrations (axial hyperkinesia) may appear to be self stimulating or sexual in nature. Jackknifing refers to abrupt bending at the waist.</p>
Gait/walking Disorder	<p>A disorganized walk (ataxia) may be as subtle as a foot rolling in occasionally, or as dramatic and absurd as a Monty Python routine. The patient may appear clumsy, stumbling, clomping or drunk. An inability to start walking, as if glued to the floor and then an inability to stop, or a shuffling walk are characteristic of tardive Parkinsonism.</p>
Oral Facial Symptoms	<p>Oral-mandibular/buccal-lingual symptoms include chewing motions (sometimes called 'Wrigley Sign'), biting with nose wrinkling ('Rabbit Syndrome'), tongue probing in the cheek ('Bon Bon Sign'), grimacing, pouting or repetitive swallowing. The jaw may open or shut or lock (trismus/lockjaw) making eating difficult. The tongue may protrude rapidly ('Fly Catcher') or hang flaccidly (tonic). The patient may make sucking/kissing/smacking/clicking noises. The patient may bite their own cheeks or tongue. Eyebrows may raise ('Spock eyebrows') or lower making the person appear haughty or angry. Symptoms confined to the lower face may be called Miego's Syndrome. Tooth grinding (bruxism) may occur during sleep. Some symptoms can be aborted by touching the lips or other tricks. Some patients with tardive Parkinsonism lack facial expressions (mask-like faces) and they may drool.</p>

Finger movements	Finger movements often resemble playing ‘Air Guitar’, ‘Air Piano’ or a particular movement called ‘milkmaid grip’. Writer’s cramp is a severe spasm of the entire hand or arm. The opposing arm may also cramp. This is more than fatigue and may be induced by fine motor activities other than writing. ‘Pill rolling’ finger movements (rubbing the thumb and fingers in a motion similar to the gesture meaning ‘money’) are more common in drug-induced Parkinsonism.
Limb symptoms	Flailing movements involving a whole limb may appear combative like a punch or karate kick (ballismus), or may appear like raising a hand to ask a question. This is one of the few movements that occurs during sleep. Some patients with tardive Parkinsonism have limb movements that are jerky and have a ratchet-like quality (cog wheel rigidity).
Eye symptoms	Blinking of both eyelids (blepharospasms) may be so severe that the patient is legally blind. The eyes may be rolled in any direction (oculogyric crisis).
Vocalizations, breathing, swallowing	Vocal tics such as grunting, throat clearing, swearing (coprolalia), and echoing words or sounds (echolalia) are possible. The vocal cords may spasm (dysphonia) making the voice choppy, quavery, breathy or cause a hoarse sounding noise when breathing in (stridor). The vocal cords may clamp shut (Laryngospasm/ obstructive apnea/dysepnea). The speech may be slurred (dysarthria) or have a quality normally associated with brain damage (bulbar). Swallowing may be uncoordinated (dysphagia).

General symptoms	
Medical Term	Description/examples
Akathisia	An inner feeling of restlessness, which compels the patient to pace, march, fidget or wiggle, although some patients are able to sit still. In infants, this is more likely to look like air boxing or air cycling. Restlessness may manifest as insomnia or be perceived as an uncomfortable inner vibration. Patients may call akathisia anxiety.
Chorea/choreic	Dance-like movements of any body part or the whole body.
Myoclonus/ myoclonic	Involuntary movements that are sudden and violent in appearance as if struck by lightning or hit by an invisible assailant.
Tics	Gilles de la Tourette Syndrome may be drug induced.
Vermicular/ atheoid	Worm-like writhing movement of any body part or the entire body.
Bradykinesia	Slowing of voluntary movements (bradykinesia) can affect any body part or the whole body. In rare cases there can be a complete lack of movement (akinesia).
Resting Tremor	Shaking of a resting limb or tongue that tends to subside during deliberate movements. The opposite of alcohol induced tremors which are worse during intentional movement.
Neuroleptic Malignant Syndrome	The most dangerous side effect of anti-psychotic drug is Neuroleptic Malignant Syndrome. This potentially fatal reaction is characterized by “lead pipe rigidity,” high fever, dehydration, sweating, elevated blood pressure, fast heart rate and respiration, agitation, elevated white blood cell count, difficulty swallowing and autonomic instability.
Paroxysmal	Very abrupt movements

Abnormal Involuntary Movement Scale (AIMS)

Examination Procedure

Either before or after completing the Examination Procedure observe the person unobtrusively, at rest (i.e., in a waiting room).

The chair to be used in this examination should be a hard one without arms.

1. Ask the person to remove their shoes and socks.
2. Ask the person whether there is anything in his/her mouth (i.e., gum, candy, etc.) and if there is, to remove it.
3. Ask the person about the current condition of his/her teeth and if he/she wears dentures. Do the teeth or dentures bother the person now?
4. Ask the person whether he/she notices any movements in their mouth, face, hands or feet. If yes, ask them to describe the movements and to what extent these currently bother them or interfere with their activities.
5. Have the person sit in the chair with their hands on their knees, legs slightly apart, and feet flat on floor. (Look at their entire body for movements while they are in this position.)
6. Ask the person to sit with their hands hanging unsupported. If they are male, the hands should hang between the legs, if they are female and wearing a dress, the hands should hang over the knees. (Observe hands and other body areas.)
7. Ask the person to open their mouth. (Observe the tongue at rest within the mouth.) Do this twice.
8. Ask the person to tap their thumb with each finger as rapidly as possible for 10-15 seconds, separately with the right hand, then with the left hand. (Observe facial and leg movements.)
9. Flex and extend the person's left and right arms, one at a time. (Note any rigidity.)
10. Ask the person to stand up. (Observe in profile. Observe all body areas again, hips included.)
11. Ask the person to extend both arms outstretched in front with palms down. (Observe trunk, legs, and mouth.)
12. Have the person walk a few paces, turn, and walk back to chair. (Observe hands and gait.) Do this twice.

(SAMPLE)

ABNORMAL INVOLUNTARY MOVEMENT SCALE (AIMS)

FACIAL AND ORAL MOVEMENTS	1	Muscles of facial expression e.g., movements of forehead, eyebrows, periorbital area, cheeks. Include frowning, blinking, smiling, grimacing of upper face	0	1	2	3	4
	2	Lips and Perioral Area e.g., puckering, pouting, smacking	0	1	2	3	4
	3	Jaw e.g., biting, clenching, chewing, mouth opening, lateral movement	0	1	2	3	4
	4	Tongue Rate only increase in movement both in and out of mouth, NOT inability to sustain movement	0	1	2	3	4
EXTREMITY MOVEMENTS	5	Upper (arms, wrists, hands, fingers) Include choreic movements (i.e., rapid, objectively purposeless, irregular, spontaneous), atheotoid movements (i.e. slow, irregular, complex, serpentine). Do NOT include tremor (i.e., repetitive, regular, rhythmic)	0	1	2	3	4
	6	Lower (legs, knees, ankles, toes) e.g., lateral knee movement, foot tapping, heel dropping, foot squirming, inversion and eversion of foot	0	1	2	3	4
TRUNK MOVEMENTS	7	Neck, shoulders, hips e.g., rocking, twisting squirming, pelvic gyrations. Include diaphragmatic movements.	0	1	2	3	4
GLOBAL MOVEMENTS	8	Severity of abnormal movements (based on highest single score on above items)	0	1	2	3	4
	9	Incapacitation due to abnormal movements	None				
			Normal	0			
			Minimal	1			
			Mild	2			
			Moderate	3			
Severe	4						
10	Client awareness of abnormal movements	No awareness	0				
		Aware, no distress	1				
		Aware, mild distress	2				
		Aware, moderate distress	3				
		Aware, severe distress	4				
DENTAL STATUS	11	Current problems with teeth and/or dentures	No	1			
		Yes	2				
	12	Does Client usually wear dentures?	No	1			
		Yes	2				

Dyskinesia Identification System (DISCUS)

The Dyskinesia Identification System: Condensed User Scale (DISCUS) was developed as a standardized rating scale to evaluate patients for signs of tardive dyskinesia. The DISCUS total score may be followed over time to assess a patient’s response to different therapeutic interventions.

Patient Evaluation

A standardized evaluation form was developed for recording clinical findings.

Each movement is scored according to the following schema:

Level	Description	Score
Not Present	Movements not observed or some movements observed but not considered abnormal	0 1 2 3 4
Minimal	Abnormal movements are difficult to detect or movements are easy to detect but occur only once or twice in a short non-repetitive manner	0 1 2 3 4
Mild	Abnormal movements occur infrequently and are easy to detect	0 1 2 3 4
Moderate	Abnormal movements occur frequently and are easy to detect	0 1 2 3 4
Severe	Abnormal movements occur almost continuously and are easy to detect	0 1 2 3 4
Not assessed	An assessment for an item is not able to be made	NA
		Total Score:

15 movements seen in tardive dyskinesia divided into 7 body areas as follows:

Patient's Name:	
Person Completing Exam:	
Date:	
Body Area	Movements
Facial	Tics
	Grimaces
Ocular	Blinking
Oral	Chewing or Lip smacking
	Puckering, sucking, or thrusting lower lip
Lingual	Tongue thrusting or tongue in cheek
	Tonic tongue
	Tongue tremor
Head, Neck, Trunk	Athetoid myokymic lateral tongue
	Retrocollis or torticollis
Upper Limb	Shoulder or hip torsion
	Athetoid myokymic finger-wrist-arm
Lower Limb	Pill rolling
	Ankle flexion or foot tapping
	Toe Movement

Total Score = _____
 _____ = SUM (points for all 15 items)

Interpretation:

The DISCUS total score > +5 is a valid measure of dyskinesia.

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SECTION 8

H **EALTH** **I** **NSURANCES**

Physical Health: Health Care Insurance 101

Health care insurance coverage comes in many forms, and coordinating benefits can be extremely cumbersome. Dealing with multiple insurance companies can become a nightmare, and so we will attempt to discuss and define different insurance coverage in order to assist you through this maze.

There are three (3) categories of coverage: Private, Medicare (MC), and Medicaid/Medical Assistance (MA). Within these three areas are sub-categories that would take pages and pages of text to explain. We will therefore try to simplify this information and provide resources in the form of web pages and telephone numbers so that you can research and expand your knowledge in this area.

Private Insurance

The first type of insurance coverage is private insurance. There are literally hundreds of companies; too many to name (i.e., Blue Cross/Blue Shield). The most important fact to remember is that **private insurance is always the primary payer**. For example, if a consumer has private insurance and Medicare coverage, the private pays first.

Private insurance is either bought by a consumer, a parent or offered by an employer (for free or the employer pays a percentage). There is usually a monthly premium for this coverage, which can be very steep. The consumer will probably have to pay a small deductible and/or co-pay when they receive health care services. The private insurance company will most likely have a Member Services Department to assist the consumer regarding health care benefits. The consumer or the people helping to support the consumer are responsible for coordinating benefits. Utilizing Member Services may [assist someone](#) in coordinating benefits.

Medicare (MC)

Medicare is a **federally funded** health care coverage program for people over 65 years of age, under 65 years of age with a disability (i.e., SSDI), or people of all ages with End-Stage Renal Disease (ESRD). The Centers for Medicare & Medicaid Services (CMS) is the federal agency that oversees Medicare. In order to secure Medicare, the consumer must enroll through their local Social Security Administration (SSA). You can find your local SSA by logging on to www.socialsecurity.gov or call toll free #1-800-772-1213.

Within the Medicare system there are four (4) types of insurance to choose: Original Medicare (Parts A & B), MC Advantage (Part C), MC Supplemental (Medigap) and Medicare Prescription Drug Plan (Part D).

Here are some important facts about Medicare coverage and what is offered:

1. Original Medicare

- Medicare comes in two parts: Part A and Part B.
- Part A covers hospitalizations, skilled nursing facilities (not long term), some home health aid & hospice care.
- Part A does not cover monthly premium.
- Part B covers medical services – physician visits, durable medical equipment, clinical lab work, specialized therapies, outpatient behavioral health, etc.
- Part B pays for some preventative services including exams, lab tests and screening shots.
- The consumer pays a monthly premium for Part B, which is automatically deducted from their social security check.
- Medicare pays 80% and the consumer is responsible for 20%; and any other co-pays/deductibles unless multiple insurance coverage is available to consumer.
- The health care provider must be participating (enrolled in Medicare) and “accept assignment” for full payment.
- There is a Coordination of Benefits department (when insurance is involved) and a “Carriers” department to contact regarding claims, billing, and issues.
- Medicare does not cover dental health, hearing aids, most hearing exams, long-term care, eyeglasses, and limited coverage traveling outside the United States.

If someone you know holds private and Medicare insurance coverage, Medicare always pays last! The consumer coordinates benefits.

Following are other plans Medicare offers to its recipients. These plans are voluntary and the consumer must pay a premium for the coverage. They are:

2. Medicare Advantage (Part C) includes MC Private Preferred Organizations (PPO), Managed Care plans (MCO), Specialty plans, and Fee-for-Service plans. (Offered by private insurance companies)

- To qualify, the consumer must be enrolled in both Part A and Part B
- Usually an additional monthly premium applies besides the monthly Part B premium
- Covers some co-pays and deductibles
- The consumer chooses a plan – *e.g. Keystone 65 Complete*
- Some may follow a network/referral system
- Includes prescription drug coverage as part of the plan
- Some limitations may apply (e.g. \$1500. annual cap on prescriptions)
- Does not need a Medigap policy

3. Medicare Supplemental (Medigap) fills the “gap” in Original MC plan (Offered by private insurance companies)

- Covers “gaps” (i.e., co-pay) and some plans offer prescription coverage,
- Plans H, I, and J
- High monthly premium involved – from \$90. to \$440

- People with dual coverage of private/original MC, original MC/Medicaid, or Medicare Advantage Plan do not need gap insurance.

For more general information regarding Medicare coverage, visit your local Medicare office, call the toll free #1-800-633-4227, or go to the website www.medicare.org or www.medicare.gov. Another good resource is through the Center for Medicare and Medicaid Services at www.cms.hhs.gov or call toll free #1-866-542-3015.

For free local health insurance counseling, contact the State Health Insurance Program (SHIP). SHIP is a state program that receives federal dollars to counsel people regarding Medicare benefits. In Pennsylvania, the Department of Aging created APPRISE, the SHIP program to assist people to understand Medicare options. It is a volunteer-based initiative managed by Coordinators and is available through Pennsylvania's 52-county Area Agencies on Aging. For more information, go to www.aging.state.pa.us/aging or call 1-800-783-7067.

4. Medicare Prescription Drug Plan (Part D) is offered by independent insurance companies and other private companies approved by Medicare.

The Medicare Modernization Act (MMA) of 2003 gave people more choices in how to get current health care benefits and added new benefits. The Medicare Prescription Drug Plans (Medicare Part D) started in January of 2006 to help pay for prescription drugs. (See **appendix “The Facts about Medicare Prescription Drug Plans”**)

- Optional plan available to all Medicare beneficiaries
- Provided by private Prescription Drug Plans (PDPs)...options include (1) stand-alone plans (maintain Original Medicare coverage) or (2) Medicare Advantage plans (provides all Medicare-covered healthcare including prescriptions).
- The consumer chooses the drug plan and pays a monthly premium
- Covers both brand name and generic drugs with different co-pays
- Each plan uses formularies and prior authorization processes
- Each plan is required to cover at least 2 drugs from every category/class of drugs identified in its classification system.
- Each plan is required to include within its formulary, a majority of the medications in the following categories/classes: antidepressants, antipsychotics, anticonvulsants, antineoplastics (AKA anti-cancer), immunosuppressants and antiretrovirals (HIV/AIDS).
- Plans are *not* required to cover medications in the following categories: 1.) Benzodiazepines, 2.) barbiturates, 3.) some over-the-counter (OTC) medications or 4.) drugs covered by MC Parts A & B.

For more detailed information regarding drug formulary plans within each MC Drug Plan, go to the www.medicare.gov website and search for “*Formulary Finder*” and “*Medicare Prescription Drug Plans*”. This is the best place to research and compare different plans, co-pays and formularies for consumers.

As of January 1, 2006, for people with Medicare and Medicaid who are considered “dually eligible” Medicare, *not* Medicaid, will be the primary payer of prescription drug costs.

Medicaid/Medical Assistance (MA)

(If other insurance is involved, *Medicaid is always the payer of last resort!*)

The third type of health care coverage is Medicaid also known as Medical Assistance or ACCESS. Medicaid/Medical Assistance (MA) is a public assistance grant program administered by the Commonwealth of Pennsylvania Department of Public Welfare (DPW). The application and qualification process for MA is conducted through a local County Assistance Office (CAO). It provides health care coverage to low income individuals of all ages and covers most healthcare needs including hospitalization, outpatient care, dental care and medications.

The Commonwealth of Pennsylvania has a health care system in place for people on MA. This health care delivery system is called fee-for-service (FFS). State and federal governments “match funds” to provide health care coverage for people who are “needy”.

Remember, with both private insurance and Medicare coverage, Medicare pays last and you coordinate benefits. With Medicare and Medical Assistance, Medicare is primary and Medicaid is payer of last resort! MC/MA will coordinate benefits.

Someone is determined to be “needy” under three (3) categories:

- Medically
- Special needs condition
- Receiving Supplemental Security Income (SSI).

In order for a person to be determined “eligible”, they must file an application with their local County Assistance Office (CAO). Once eligibility is determined, an “ACCESS” card will be issued.

In 1996, the Commonwealth of Pennsylvania introduced a new health care delivery system in the form of “managed care”. The purpose of this system was to improve the quality, accessibility, and continuity of health care for people on MA. The new program was termed *HealthChoices*. A Medical Assistance health maintenance organization (MA MCO), contracted with the state to manage a person’s health care. An individual may apply for an MA MCO by calling the HealthChoices hotline # 1-800-440-3989 or access the local county assistance office.

As of today, in the Southeast region of Pennsylvania there are three (3) MA MCO plans from which to choose. They are:

- AmeriChoice Health Plan
- Health Partners Health Plan
- Keystone Mercy Health Plan.

All three (3) plans offer primarily the same type of coverage for health care services and supply identification cards to people enrolled. However, it is best to compare options before making a decision. It is also important to note that all three MA-MCOs maintain a “Special Needs Unit” to aid consumers in acquiring healthcare treatment, services or items such as Durable Medical Equipment (DME) needed.

If you support someone with a “special need” and are having difficulty gaining services or equipment, call the particular MA MCO and ask to speak directly with the Special Needs Unit (SNU). A “Letter of Medical Necessity” may be needed to which the SNU can help direct the process and explain the criteria.

There are still some counties in Pennsylvania receiving health care services through FFS. MA recipients in the Southeast region of Pennsylvania (including Bucks, Delaware, Chester, Montgomery, and Philadelphia counties), Southwestern and Lehigh/Capital zones receive all their health care services (physical and behavioral) in a managed care delivery system.

How the Medicare Prescription Drug Benefit (Part D) affects Dual Eligibles:

“Dual Eligibles” are considered those people who have both Medicare and Medical Assistance. As a result of the Medicare prescription drug benefit beginning 1/1/06, all dual eligibles were disenrolled from Medical Assistance MCO’s (HealthChoices, ACCESS Plus) but continued to have fee-for-service Medical Assistance coverage.

As of 1/1/06, dual eligibles maintain prescription drug coverage through two options:

- Maintain Medical Assistance “fee-for-service” benefit and choose a separate Medicare Prescription Drug Plan (PDP) or
- Enroll in a Medical Assistance – Medicare Advantage Plan (MA-PDP) such as Keystone 65 Complete (constituent of Keystone Mercy) or Senior Partners Silver Plan (Health Partners).

Navigating the System: How to Get What People Need From Their Medical Assistance Health Maintenance Organization

(Philadelphia Coordinated Health Care, 1998)

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1. Health Information Log
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I. Introduction

In 1996, the Commonwealth of Pennsylvania introduced HealthChoices, a new mandatory health care delivery system, for people on Medical Assistance (MA). The inception of HealthChoices or “managed care” offered people on MA better quality health care, better access to health care, and a closer oversight of health care services offered throughout the Commonwealth.

The new system formed with health maintenance organizations (HMO’s), providing each individual with a Primary Care Physician (PCP) to oversee all of their health care needs. The MA HMO would provide all health services that were deemed medically necessary.

Although this new health care delivery system did initially present some challenges to people using it, it has also offered improved health services for those on MA. The MA HMO’s have

Special Needs Units designed to assist anyone who believes they have a special need and are seeking help in locating quality health care services within their community.

HealthChoices ensures that each individual has a “home-base” for all of his or her health care needs through their Primary Care Physician. This “home-base” model of care also helps to ensure continuity and coordination of health services for each individual.

Managed care has become an important part of the lives of people with disabilities. Some people are very satisfied with the changes in health care; others are still frustrated. We hope that this information will be a tool for helping to change frustration into satisfaction toward the goal of accessing quality health care services within the community.

II. Being An Informed Health Care Advocate

A person’s relationship with his or her Primary Care Physician (PCP) is the strongest one to build in the managed health care system. A PCP holds the keys to smooth sailing through the Medical Assistance Health Maintenance Organization (MA HMO) waters.

The functions of the PCP are to:

- Coordinate all aspects of an individual’s medical care
- Authorize referrals to Specialists
- Order all diagnostic testing (i.e., x-rays, CT [cat] scans, etc.)
- Be available by telephone 24 hours a day
- Provide treatment when a person is ill and help prevent illness
- Write prescriptions for medications and durable medical equipment (i.e., wheelchair, hospital bed, etc.)

In order to navigate an MA HMO successfully, you need to be an informed health care advocate. Below, we have included a list of questions, which we hope will be helpful and we also suggest that you add your own. Reflecting on these questions and changing any “no” answers into “yes” ones will make you a more active health care advocate who is better able to secure good health care services for the individuals you support.

Are You an Active Health Care Advocate?

- Do you take a list of questions or concerns when you go to the doctor with the person?
- Do you encourage the doctor to talk to and with the person rather than you?
- Do you make sure that all of the individual’s symptoms are described?
- Do you bring a current list of medications with you?
- Do you ask for information about possible side effects to prescribed medications?
- Do you ask for referrals to Specialists when other care is needed?
- Do you feel comfortable asking for referrals to Physical, Occupational, or Speech therapists?
- Do you keep asking until you understand what the doctor is telling you?
- Do you get any needed instructions in writing from the doctor?

III. Tips for Navigating the MA HMO System

It is the individual's **right** as a health care consumer to request or have you request the following important materials from their MA HMO:

- Member handbook explaining the benefits package
- Provider directory which lists medical providers that should be utilized in the MA HMO network
- Member card with identification number.

It is important to keep a "Health Information Log" to help you centralize this and other very important information by keeping it all on one sheet of paper in an accessible place.

When you call the MA HMO with a problem, remember to record the names of people you spoke with and the content of the telephone conversation. You can use the "Telephone Documentation Log" (See Appendix B) to document the calls. Save and put all telephone records and correspondence received from and sent to the MA HMO in a safe place.

The gathering and coordinating of information go hand in hand. Together they will help to more easily and effectively communicate the person's needs. Clear and complete information may clarify any questions and may even resolve conflicts before they occur.

Becoming an active and informed health care advocate can support you in navigating the MA HMO system with ease and confidence.

IV. Solving Problems

If you find the person you support in stormy waters with a problem you cannot resolve, you may be able to calm the waters by speaking with the PCP. If your problem still remains unresolved, you can request a second opinion from another physician within the MA HMO network.

Another avenue to assist you in problem solving is the Special Needs Unit (SNU) of the MA HMO. The SNU is available to provide people with additional support regarding their health care needs. The Southeast Regional MA HMO SNU telephone numbers are listed below.

- AmeriChoice Health Plan: SNU #215-832-4571
- HealthPartners Health Plan: SNU #215-991-4370
- Keystone Mercy Health Plan: SNU #800-521-6860
- Keystone 65 Complete Health Plan: Member Hotline #800-645-3965

Also, remember that you can always contact Philadelphia Coordinated Health Care (PCHC) for support to access quality health care to resolve your dilemmas.

Another way to get your needs met is through the Program Exception Process by showing that the health care service is medically necessary. When requesting special medical services or durable medical equipment through this process utilize the following:

- Have the prescribing doctor (PCP, Specialist, and/or Dentist) write a letter of medical necessity with the following information: a diagnosis, a description of the condition, a description of possible extenuating circumstances, a description of the preventive qualities of the service or equipment requested; and the cost effectiveness of that service or equipment.
- The letter of medical necessity needs to be submitted to the MA HMO for approval.
- At the same time, mail or fax the letter of medical necessity and any other pertinent information (i.e., prescription/s bill/s, etc.) to the attention of the Special Needs Unit of the MA HMO.

No Resolution in Sight

When there is no resolution in sight, there are other alternatives. The person should file a complaint, grievance, or appeal with the MA HMO. To help support them in this process, we have included the addresses of Grievance and Appeal Committees for the Southeast Regional MA HMO's and a sample grievance letter (See Appendix C). You can also refer to information provided by the Pennsylvania Health Law Project which can be found on their website at www.phlp.org. They will explain what to do when you disagree with and are denied services by the MA HMO.

When Change is Necessary

If navigating the waters of the MA HMO gets too choppy and change becomes necessary, you can “bail out” the person you support. The individual has the right to change either their MA HMO or PCP or both.

To change the PCP, call the Member Services of the MA HMO with the name and address of the new PCP. To change the MA HMO, call the *HealthChoices Hotline at 1-800-440-3989* with the name of the new MA HMO and PCP.

V. Grievance and Appeals

In order to support you in this process, we have listed below the addresses of Grievance Committees and the Board of Appeals for you to utilize. Most importantly, we have provided a “recommended” list of documentation for you to gather when challenging an MA HMO regarding denied services.

Grievance Committees

AmeriChoice Health Plan
Attn: Grievance Coordinator
100 Penn Square East, Suite 900
Philadelphia, PA 19107

HealthPartners Health Plan
Attn: Grievance Coordinator
833 Chestnut St., Suite 900
Philadelphia, PA 19107

Keystone Mercy Health Plan
Attn: Grievance Coordinator
PO Box 41820
Philadelphia, PA 19101

Boards of Appeal

Office of Hearing and Appeals
Department of Public Welfare
6th Floor
Bertolino Building
PO Box 2675
Harrisburg, PA 17105

Bureau of Health Care Financing
Department of Health
Room 1026
Health and Welfare Building
PO Box 90
Harrisburg, PA 17108

Recommended List of Documentation to File a Grievance or Appeal

- Letter of medical necessity from PCP
- Supporting letters of medical necessity from other medical Specialists
- (i.e., Podiatrist, Cardiologist)
- Prescriptions from PCP
- Previous correspondence received from MA HMO
- Statement of what benefits are covered by Medical Assistance
- Denial letter/s from MA HMO, Medicare, and/or private insurance
- Pictures of injury, wound, etc.
- Telephone documentation recording contacts with MA HMO representatives

VI. Conclusion

*Do you need a helping hand in navigating the system?
Call PCHC at (215) 546-0300, extension 3685.*

For questions or concerns regarding any medical or nursing issues, please feel free to call the number listed above and request to speak to a Nurse.

For questions or concerns regarding any insurance and/or managed care issues, please call the number listed above and ask to speak with a Health Care Technical Assistance Specialist.

We hope this information is helpful to you on your journey to obtain quality health care services for the individuals you support.

Good Luck and Smooth Sailing!

Behavioral Health Insurance

Behavioral health is a separate entity from physical health and is also being administered by a managed care delivery system. Overseen by the Commonwealth of Pennsylvania's Office of Mental Health and Substance Abuse Services (OMHSAS), participating counties are required to ensure quality behavioral health care. Once a person is determined eligible for MA, they are automatically enrolled into a behavioral health plan within their county of residence and will utilize their "access" card to identify themselves as eligible.

Each county in the Southeast region of Pennsylvania is responsible for providing behavioral health services to MA recipients. All Southeast regional counties contract with a behavioral health managed care organization (BH-MCO). They are:

- Bucks County – Magellan Behavioral Health
- Chester County – Community Care Behavioral Health Organization (CCBHO)
- Delaware County – Magellan Behavioral Health
- Montgomery County – Magellan Behavioral Health
- Philadelphia County – Community Behavioral Health (CBH)

To provide behavioral health care services to enrollees, BH-MCO's must establish a provider network, comprised of behavioral health care professionals and facilities that deliver services. The benefit packages for consumers are based on category of assistance, age, and/or the existence of Medicare coverage. Some of the services provided by the BH-MCO are:

- Inpatient Psychiatric Hospital
- Inpatient/Non-Hospital D&A Detox/Rehab
- Psychiatric Outpatient
- Psychiatric Partial Hospitalization
- Targeted Case Management
- Mental Health Services
- Crisis Intervention Services.

For more information, contact the Southeast HealthChoices hotline at 1-800-440-3989 or call your local County Assistance Office and at either place you can speak with an Enrollment Specialist.

REFERENCES

- Navigating the System: How to Get What People Need From Their Medical Assistance Health Maintenance Organization. A Guide for Health Care Advocates Who Support Philadelphians with Mental Retardation and Other Developmental Disabilities. Copyright@1998.
- www.dpw.state.pa.us
- www.medicare.gov
- www.cms.hhs.gov

SECTION 9

SUBSTITUTE HEALTH CARE DECISION MAKING AND END OF LIFE PLANNING

Substitute Health Care Decision Making and End of Life Planning

Substitute Health Care Decision Making

The process of health care decision-making involving individuals with developmental disabilities was guided by Mental Retardation Bulletin #00-98-08 entitled “Procedures for Substitute Health Care Decision-Making”(Pennsylvania Office of mental Retardation, 1998). At the time this Guide went to press, the Office of Developmental Programs was working on a new, as yet unnumbered draft bulletin for surrogate health care decision making in order to comply with Pennsylvania Act 2006-169 (Act 169).

According to the 1998 bulletin, autonomy of persons who have the capacity to make particular health care decisions must be respected. These individuals must receive all information necessary to give informed consent or refuse a medical intervention. In cases where a health care decision is necessary and the individual does not have the capacity to decide, decisions must be made on the individual’s behalf. The bulletin offers guidelines for these types of decisions. Act 169 and the draft bulletin incorporate complex provisions. Each provider may wish to draft new policies and procedures to comply with Act 169 and also the draft bulletin when adopted.

End of Life Planning

Planning for an individual’s wishes for end of life treatment should be encouraged and supported. The ideal is to attempt this planning before a life-ending situation, such as a terminal illness or injury, arises. This may be a difficult process if the person is unable to communicate those wishes to others.

Individuals who have the capacity to make health care decisions may be able to complete an Advance Directive or name a Health Care Proxy to make decisions for them when they cannot.

The majority of people with a developmental disability will not be able to complete an Advance Directive. Because no person other than the individual may complete this Directive, many people with a developmental disability will be unable to participate in this type of end of life planning process. When this is the case, and the person cannot participate in decisions arising at the end of life, the guidelines available in the Mental Retardation Bulletin regarding “Procedures for Substitute Health Care Decision Making” will be used to guide health care professionals in end of life treatment.

Although many individuals will be unable to complete an Advance Directive, people who have known the individual (for example, family, friends, team members) may be able to express in writing what they believe the individual person would want, based on past experiences and behaviors. This is not the same as an Advance Directive. Health care professionals may choose to use this information in framing their treatment options based on the individual’s past experiences. This type of document is also beneficial for

caregivers who have supported individuals throughout their lives and now have input into the end of life process.

REFERENCES

- Pennsylvania Office of Mental Retardation (1998). *Mental Retardation Bulletin #00-98-08, Procedures for substitute health care decision making*. Harrisburg, PA. Pennsylvania Department of Human Services.

APPENDICES



POLICY STATEMENT

AAMR

ADVOCACY

POLICY STATEMENT

Advocacy is essential in maintaining or improving the quality of life for people with mental retardation and related developmental disabilities¹.

ISSUE

Our constituents may lack the support of advocates to:

- Know, understand and assert their rights.
- Practice self-determination.
- Practice self-protection.
- Obtain needed services.
- Identify and overcome barriers to and discrimination in the community.
- Be protected from abuse and neglect.

POSITION

Advocacy is vital in improving and sustaining quality of life for our constituents. To be successful, advocacy must take place at both the individual and the system levels.

Individuals

Advocates should be knowledgeable, trained, and grounded in basic principles respecting the rights and dignity of children and adults as set forth in these position statements.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

Advocates must communicate effectively with our constituents, encouraging them to express and act on their thoughts, choices, and feelings about issues and proposed solutions. The advocate and the individual must be able to understand each other. The advocate should exercise great care to ensure that the person with mental retardation fully understands the benefits and risks of any decision. In making decisions, people should be encouraged to consult with the important people in their lives. Advocates have an ethical obligation to represent the desires and needs of the person they represent, regardless of their own personal opinions on the matter.

In certain circumstances, parents and other legal representatives may need to be involved in making decisions with and on behalf of the individual. Advocates must be careful to recognize and set aside their own needs and desires that may conflict with those of the individual they are advocating for. If there is a conflict of interest, the advocate should withdraw from the decision-making.

Systems

Individuals should have access to Protection and Advocacy systems mandated by state and federal laws that:

- Are free from government influence and control.
- Are free from conflict of interest.
- Are adequately funded and staffed.
- Provide advocacy on their behalf even though a formal complaint has not been filed.
- Have the capacity to bring together all other community resources available in pursuit of the appropriate remedies.
- Use multiple advocacy strategies, such as information and referral, mediation, legal action, and legislative and regulatory solutions.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT

AAMIR

AGING

POLICY STATEMENT

Many people with mental retardation and related developmental disabilities¹ who are aging deserve the same opportunities to enjoy full lives in their communities as other older people. They are entitled to community support, including help from those agencies that serve the needs of all senior citizens.

ISSUE

More of our constituents are living longer. They want to enjoy their older years in the same manner as other people their age. Like other older Americans, these individuals require greater levels of support to allow them to live full, active, and healthy lives. Unfortunately, many of our older constituents lack basic health care, housing, and specialized services tailored to the needs of older people. Additionally, their family members lack information and resources to help them assist the person who is growing older.

These problems are compounded because many community-based services for senior citizens are not prepared to meet the special needs of older adults with disabilities. Likewise, many disability-based organizations have historically not recognized the problems of older adults with disabilities and are not prepared to address these special needs.

POSITION

As they age, our constituents must be recognized as respected members of the community. Services to people who are older must accommodate the supports needed by this population.

Our constituents who are growing older should:

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Be afforded the same rights, dignity, respect, and opportunities as other older people in their communities.
- Have access to housing, health care, social services, transportation, and other services available to older Americans in their communities.
- Receive supports to live, work, play, and retire when, where, and how they prefer.
- Be free from the fear of inappropriate institutionalization due to age-associated decline or infirmity.
- Have access to pension plans that include the same payment provisions afforded other retirees or to alternative financial supports available to older persons who no longer work.

Public policy considerations include:

- Legislation and regulations affecting older Americans should refer distinctly to the eligibility of our aging constituents.
- Programs that support caregivers of older people with disabilities should include support of older parents who are the primary caregivers for their adult children.
- Federal and state resources should vigorously support research and best practices to meet the needs of older persons with disabilities.
- Professionals should be prepared to deal with the issues related specifically to our aging constituents.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT



HEALTH CARE

POLICY STATEMENT

People with mental retardation and related developmental disabilities¹ must have dependable, high quality health care in the community and affordable, comprehensive health insurance.

ISSUE

Too many of our constituents have faced numerous challenges, including life-threatening barriers, in accessing timely and appropriate health care. Problems in the community include inability to obtain appropriate quality services, lack of access to specialists, and healthcare professionals who refuse to serve or limit the options made available to this population. Many communities in fact lack health professionals overall but especially those trained to meet the needs of our constituents. To add to the problem, health insurance coverage is frequently unavailable or prohibitively expensive.

POSITION

Our constituents must have universal access to appropriate, affordable, accessible, timely, and comprehensive medical and dental treatment throughout their lives.

- Disability must not be a factor in the decision to provide, delay, or withhold treatments or to provide or receive organ transplants. The person's medical condition and welfare must be the basis for the decision.
- Reasonable accommodations must be available for those who do not have the capacity to make health care decisions.
- Health Professionals must receive specialized training to assure maximum health and to prevent secondary conditions among our constituents. Furthermore, the overall shortage of nurses and other trained professionals must be addressed.
- Reimbursement rates for health care professionals must reflect the fact that many people with disabilities have greater health care needs and thus require more time with a health care provider. Reimbursement rates must not provide a disincentive for healthcare professionals to provide services.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Treatment must be high quality and:
- Based on a broad definition of medical necessity. This must include not only overcoming or preventing illness but also maintaining or preventing additional deterioration of existing functioning.
- Not denied on the basis of mental retardation.
- Given only with the informed consent² of the individual or the surrogate decision-maker³ and include the use of advance directives⁴ when applicable.

Health care reform must be based on the following principles:

- Non-discriminatory: Prohibits denials for pre-existing conditions or mental retardation; prohibits practices which set higher premiums solely because of the existence of a disability; and provides timely access despite disability, age, race, location, income, health status, or change in address.
- Comprehensive: Ensures a wide array of services including active and preventive medical care, mental health care, rehabilitation, personal assistance, and support.
- Appropriate: Ensures services based on individual need, preference, and choice.
- Equitable: Ensures that people with disabilities will not bear a disproportionate share of the costs.
- Efficient: Maximizes quality care and minimizes administrative costs.

Other considerations include:

- Informed consent. The decision to accept or refuse treatment requires informed consent. Informed consent requires that the individual decision-maker or surrogate decision-maker:
- Have the legal capacity to give consent.
- Be given enough information to understand the benefits and risks of the proposed treatment.
- Be offered the opportunity to ask questions and receive answers understandable to that person.
- Not be forced to accept a particular treatment through deceit or threat.
- Surrogate Decision-making. If an individual is unable to make his/her own medical decisions and does not have an advance directive such as a "Living Will," or a health care power of attorney, a

² Informed consent: voluntary, uncoerced agreement to accept a health care treatment. (Midwest Bioethics Center & University of Missouri-Kansas City, Institute for Human Development, Bioethics Forum, Fall 1996)

³ Surrogate decision-maker: a person who makes health care decisions for a patient who cannot make his or her own decisions. (Midwest Bioethics Center & University of Missouri-Kansas City, Institute for Human Development, Bioethics Forum, Fall 1996)

⁴ Advance Directive: an individual's written or oral preferences regarding life-sustaining medical treatment decisions. (Ethics Manual, American College of Physicians, 1998)

surrogate decision-maker should be appointed to make these decision before a crisis arises. People who have such authority under state laws include the parent of a minor child, the guardian/conservator of an incapacitated adult, or surrogate decision-makers designated under a health care consent law.

All decision-making by a surrogate decision-maker should be consistent with the principles expressed in the sections above regarding Healthcare and informed consent and must always be consistent with the best interests of the individual. In addition, in decisions involving the refusal of medical treatments, or nutrition and hydration when such refusal will result in the death of the individual, the legal authority of the surrogate decision-maker should be limited.

Specifically, that authority should be confined to those situations in which the person's condition is terminal, death is imminent, and any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying. However, in such situations, people with mental retardation must be provided aggressive medical treatment to relieve pain, sustenance as medically indicated, and care designed to relieve isolation, fear, and physical discomfort.

- Advance directives. These are appropriate whenever informed consent is assured and should be available and honored for individuals with mental retardation.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT



INCLUSION

POLICY STATEMENT

All Americans gain when people with mental retardation and related developmental disabilities¹ are fully included in their communities.

ISSUE

In the past, individuals with mental retardation and related developmental disabilities have often not been treated equally. They have been labeled by their disability and separated from the community. For many years they were relegated to sterile, dehumanizing institutions. Even as they have begun living in the community, they have experienced exclusion from its schools, jobs, and social life. Moreover, the services they receive frequently segregate, isolate, and focus on an individual's deficits rather than strengths and lifestyle choices.

POSITION

All our constituents have the right to participate fully in their diverse communities. Needed supports should be available and affordable so that each individual with disabilities can live, learn, work, and play with others who do not have disabilities.

Children should:

- Live in a family home.
- Grow up enjoying nurturing adult relationships both inside and outside a family home.
- Learn in their neighborhood school in a regular classroom that contains children of the same age without disabilities.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Participate in the same activities as children without disabilities.
- Play and participate with all children in community recreation.
- Have the opportunity to participate in an inclusive spiritual life.

Adults should have the opportunity to:

- Have maximum control over their lives.
- Have relationships that range from acquaintances to life partners.
- Live in a home of their choice, with whom they choose.
- Engage in meaningful work in an inclusive setting.
- Enjoy inclusive recreation and other leisure activities .
- Participate in inclusive spiritual activities.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT

AAMR

PROTECTION

POLICY STATEMENT

People with mental retardation and related developmental disabilities¹ must be protected from harm and injury and must have the tools and supports so that they can protect themselves.

ISSUE

Abuse, neglect, and mistreatment of our constituents by the general public, service providers, and even their own families are all too common. Families often lack the supports necessary to avoid undue stress as well as access to resources to help them protect their children from abuse, neglect, and mistreatment by others. Individuals living outside the family home, regardless of the size or location of the residence, are particularly vulnerable. In addition, existing laws, regulations, and policies may fail to prevent abuse and neglect.

POSITION

Protection from harm of people with mental retardation and related developmental disabilities is vital.

Children

In most situations the birth, adoptive, or foster family is the best source of protection from harm for a child. To fulfill that role, a family should have access to:

- Family support services.
- Parent support groups.
- Information and referral networks.

If the family is unable to provide necessary protection for any reason, federal, state and local child protection laws and regulations should be applied to protect the child. Any protective

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action should infringe as little as possible on the individual's and family's right to privacy and self-determination.

Adults

When an adult needs protective assistance, the best protection usually comes from the person's family, community, and friends. Protection services should be provided through adult protective agencies or advocacy groups. Individuals should be trained to better protect themselves. As with children, whenever applicable and available, the full force of the law should be applied to protect the individual.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT



QUALITY OF LIFE

POLICY STATEMENT

People with mental retardation and related developmental disabilities¹ must be able to live the lives they choose and have a good quality of life.

ISSUE

Our constituents often do not have the services, supports, and personal relationships they need to lead a full life in the community. Many are unemployed or underemployed. People encounter public policy and other barriers that keep them from choosing where they live and work. Moreover, they often lack opportunities to participate in and contribute to their communities.

POSITION

A good quality of life exists for our constituents when they:

- Receive the support, encouragement, opportunity and resources to explore and define how they want to live their lives.
- Choose and receive the services and supports that will help them live meaningful lives.
- Direct the services and supports they receive.
- Lead a life rich with friendships.
- Have their rights, dignity and privacy protected.
- Are allowed to take risks in their choices.
- Are assured of health and safety.

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Public agencies, private organizations, and individuals providing services and supports must:

- Be responsible and accountable to individuals and their families.
- Continuously improve their efforts to support individuals in leading meaningful lives.
- Be recognized when they make meaningful contributions to the quality of life for individuals.
- Be replaced when they fail to make meaningful contributions to quality of life for individuals.
- Be part of a program of ongoing monitoring, independent of the service provider, to ensure desired outcomes and the satisfaction of the people served and their families.

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENTS AAMR

RIGHTS

People with mental retardation and related developmental disabilities¹ have the same basic legal, civil and human rights as other citizens. They may need accommodation, protection and support to enable them to exercise these rights. Their rights should never be limited or restricted without due process.

Advocacy. Advocacy is essential in maintaining or improving the quality of life for people with mental retardation and related developmental disabilities.

Criminal Justice. People with mental retardation and related developmental disabilities, like other residents of the United States, have the right to justice and fair treatment in the criminal justice system, including reasonable accommodations as necessary.

Guardianship. The majority of people with mental retardation and related developmental disabilities can manage their own affairs with informal assistance and guidance from others, such as family and friends. If guardianship² is necessary, it should be tailored to the person's needs. It must be adequately monitored to ensure that the best interests of the individual are protected.

Human and Civil Rights. The human and civil rights of all people with mental retardation and related developmental disabilities must be honored, protected, and enforced.

Inclusion. All Americans gain when people with mental retardation and related developmental disabilities are fully included in their communities.

Protection. People with mental retardation and related developmental disabilities must be protected from harm and injury and must have the tools and supports so that they can protect themselves.

Self Determination. People with mental retardation and related developmental disabilities have the same right to self-determination as all people. They must have opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.

¹ "People with mental retardation and related developmental disabilities" refers to our constituency, *i.e.*, those defined by the AAMR classification and the DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

² Terminology for guardians differs by state and can include tutor, conservator, etc

Adopted: Board of Directors, AAMR
May 28, 2002

Congress of Delegates, The Arc of the United States
November 9, 2002



POLICY STATEMENT

AAMR

SELF-DETERMINATION

POLICY STATEMENT

People with mental retardation and related developmental disabilities¹ have the same right to self-determination as all people. They must have opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.

ISSUE

Many of our constituents have not had the opportunity or the support to control choices and decisions about important aspects of their lives. Instead, they are often overprotected and involuntarily segregated. Many of these people have not had opportunities to learn the skills and have the experiences that would enable them to take more personal control and make choices. The lack of such learning opportunities and experiences has impeded the right of people with these disabilities to become participating, valued, and respected members of their communities. Furthermore, state monitoring and licensure policies and practices may be contrary to the principles of self-determination.

POSITION

Our constituents, as Self Advocates, have the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives. To this end, they:

- Must have the opportunity to advocate for themselves with the knowledge that their desires will be heard and respected.
- Must have opportunities to acquire skills and develop beliefs that enable them to take greater personal control.
- Must be active participants in decision-making about their lives.

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- Must be supported, assisted, and empowered to vote and to become active members and leaders on community boards, committees, and agencies.
- Must have the primary leadership role in setting the policy direction for the self-determination movement.
- Must have the option to direct their own care and allocate available resources.
- Must be able to hire, train, manage, and fire their personal assistants.
- Must have the opportunity to be involved in governmental decisions that have an impact on their lives.

Additionally, in working with our constituents:

- Families and substitute decision-makers should be supported to understand the concept and implementation of self-determination, including the limits on their powers.
- Disability organizations should make self-determination a priority and include this important concept in their conferences, publications, advocacy, training, services, policies, and research.
- Governments should regularly review and revise laws, regulations, policies, and funding systems to promote self-determination. The affected individuals must be involved in these reviews and revisions.

The Arc's Congress of Delegates: 2004



POLICY STATEMENT

AAMIR

SEXUALITY

POLICY STATEMENT

People with mental retardation and related developmental disabilities¹, like all people, have inherent sexual rights and basic human needs. These rights and needs must be affirmed, defended, and respected.

ISSUE

For years, people with mental retardation and related developmental disabilities have been thought to be asexual, having no need for loving, fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has affected them broadly in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. Our constituents frequently lack access to appropriate sex education in schools and as adults and to training in parenting and child-rearing. At the same time, people with cognitive limitations often engage in sexual relations as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality.

Moreover, the general public maintains other out-of-date views of the sexuality of our constituents. Many people have an unfounded fear that parents with mental retardation cannot raise or financially support their children and thus will require more government support, including placement of children in the foster care system.

POSITION

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of mental retardation and related developmental disabilities, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

All people have the right within interpersonal relationships to:

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- Develop friendships and emotional relationships where they can love and be loved and start and stop the relationships as they choose.
- Dignity and respect.
- Privacy, confidentiality, and freedom of association.

With respect to sexuality, individuals have a right to:

- Sexual expression, reflective of age, social development, cultural and moral values, and social responsibility.
- Information to allow informed decisions, including sex education about such issues as safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases.
- Protection from sexual harassment as well as from physical, sexual, and emotional abuse and sexual relationships with paid staff.
- Have sexual relationships, including marriage, with individuals of their choice.

With respect to sexuality, individuals have a responsibility to:

- Consider the values, rights, and feelings of others.
- Seek input from families, friends, religious leaders, and others on the personal and societal values associated with sexuality.

With respect to the potential for having and raising children, they have the right to:

- Choices related to birth control, including the decision to have and raise children, with supports if necessary; to accept personal responsibility for these decisions; and to have control over their own bodies.
- Have, on an individual basis, access to the proper supports to assist them in raising their children within their own home.
- Choose for themselves whether or not to be sterilized, regardless of the severity of their mental retardation.



MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA

DEPARTMENT OF PUBLIC WELFARE

DATE OF ISSUE

January 9, 2004

EFFECTIVE DATE

Immediately

NUMBER

00-04-05

SUBJECT:

Positive Approaches

BY:

Kevin T. Casey

Deputy Secretary for Mental Retardation

SCOPE:

County MH/MR Administrators
Base Service Unit Directors
Community Residential MR Facility Directors
Adult Training Facility Directors
Family Living Directors
State ICF/MR Directors
NonState ICF/MR Directors

PURPOSE:

The purpose of this Bulletin is to emphasize the concept of Positive Approaches and to encourage the promotion of Positive Approaches in all programs serving people with mental retardation.

BACKGROUND:

Pennsylvania, in helping to lead a larger national trend over the past 30 years, moved away from providing services in large institutions to developing a variety of community based alternatives. In 1968, there were 12,000 individuals living in large state-operated facilities and very few individuals received services in the community. By 1990, the number of individuals living in state centers decreased to 3,900 and over 53,000 individuals were receiving services in the form of community residential programs, employment training, early intervention and family living or lifesharing. Today, only about 1,500 individuals remain in state centers while over 70,000 are receiving services and supports in communities across Pennsylvania.

The 1980s saw increasing numbers of people with mental retardation transitioning to community living. Concurrently, the need for increased quality services and supports in the community became easily apparent and people began to voice greater expectations beyond simply a system of services and supports. Self-advocates incorporated as Speaking for Ourselves in 1982 and Family Driven Support Services (FDSS) began a few years later. Individuals, their families and advocacy organizations expressed a desire to have more control over their own lives and to address issues such as restrictive and aversive procedures, maintaining contacts with family and friends and becoming an interactive part of the community.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

THE APPROPRIATE REGIONAL PROGRAM MANAGER

As part of the movement to address these issues, the Office of Mental Retardation formed a Subcommittee on Positive Approaches in 1991 and also published Mental Retardation Bulletin 00-91-05 entitled "Positive Approaches." The Subcommittee, represented by state, county and provider agency staff in each region, introduced and promoted the concept of Positive Approaches by providing training, developing resource materials, establishing communication networks and identifying the major principles of Positive Approaches that were contained in the Bulletin. Consequently, the Office of Mental Retardation adopted the concept of Positive Approaches for use in regulation and policy development, training, monitoring and providing services and supports to individuals.

Complementing the incorporation of Positive Approaches into the service system was the publication of *Everyday Lives*. *Everyday Lives* captured the vision for the future of the mental retardation system. John McKnight wrote:

Our goal should be clear. We are seeking nothing less than a life surrounded by the richness and diversity of community. A collective life. **An Everyday Life**. A powerful life that gains its joy from the creativity and connectedness that comes when we join in association as citizens to create an inclusive world.

In 1996, the Office of Mental Retardation's Statewide Training Initiative began the quarterly publication of *The Pennsylvania Journal on Positive Approaches*, and an article entitled "An Overview" appeared in this issue that conceptualized the Positive Approaches paradigm. Recent issues have focused on identifying mental illness in people with developmental disabilities and supporting people with mental retardation who have problematic sexual behaviors.

A Multi-Year Plan for Pennsylvania's Mental Retardation Service System was formulated in 1997 and the Waiting List Campaign began in 1998. A Self-Determination grant was received in 1999 from the Robert Wood Johnson Foundation. *Everyday Lives, Making It Happen* was published in 2002 and summarized ten years of progress and outlined a framework for the future.

Mental Retardation Bulletin 00-03-05, implemented in 2003 and entitled "Principles for the Mental Retardation System," took the values articulated in *Everyday Lives, Making It Happen* and listed them as a series of person-centered outcomes that serve as a guide for personal action.

Another major goal begun in 2003 is to reduce and eventually eliminate all restraints in the mental retardation system. This will be done through getting input from several counties, provider agencies, and individuals and families, and then rewriting current regulations to reflect an emphasis on positive interventions and the elimination of restraints.

A new Behavior Support Policy for state mental retardation centers was drafted in 2003 and the policy complements the principles of person-centered, positive approaches.

In summary, the Office of Mental Retardation's efforts are aimed at a diversity of positive approaches that enhance the lives of people with mental retardation as they strive to live fulfilling lives in communities across the Commonwealth.

DISCUSSION:

Much of what has been written about using positive approaches in dealing with challenging behaviors involves examining the individual's environment to see the frequency and types of choices the individual is allowed to make; how the individual does or doesn't communicate with others to ensure wants and needs are known; what physical health issues might be causing pain or agitation; what mental health issues are present and how are they impacting on behavior; and what resources, services and supports are in place to help the individual in dealing with problems over a period of many months or years.

Changing an individual's environment can be a key to resolving what might be viewed as problematic behaviors. For example, does the individual have foods that are enjoyed at meals and access to snacks when hungry? Can the individual choose different food items or does the individual get what's served, like it or not? Does the individual have opportunities to have fun by choosing an activity that is enjoyed, by being around friends, by going into the community, by enjoying a relationship? Did the individual choose the arrangement of furniture and accessory items? Does the individual have a sense of self-esteem and being valued as a person? Allowing the individual to make choices to change the environment can be a major factor in resolving behavioral issues.

What if the individual exhibiting problematic behaviors can't communicate needs, verbally or otherwise, in a manner that is understood by support staff? Language boards and other types of augmented communication should be attempted in trying to establish what the individual wants and is trying to tell others. Certain gestures and body language can be meaningful and an individual who can't communicate easily will eventually become frustrated with every interaction. Many times the problem behaviors and frustrations decrease or disappear when the individual is consistently able to communicate in a meaningful way.

Clinical assessment, diagnosis, and syndrome-related treatment are vital tools because challenging behaviors may continue to occur even when environmental and communication needs are resolved. Physical health issues can also impact an individual's behavior, e.g., arthritis pains, gastrointestinal upsets and allergies are some common conditions that can cause distress. The diagnosis and treatment of mental illness in people with mental retardation is not uncommon and consistent quality treatment can be an asset in negating problem behaviors when other efforts meet with minimal success.

When an individual's life has been impacted by severe hardships and traumas over a period of time, the process of resolving these issues can take months or years until the individual begins to develop a sense of self-esteem and satisfaction with overall life goals. Support staff need to make constant and encouraging teaching efforts to do what it takes to help the individual despite repetitive cycles of minimal progress and regression.

The following points are titled "Positive Approaches as a Paradigm"¹ and they represent a series of examples describing the concept:

- Positive Approaches (adapted from Mental Retardation Bulletin, DPWPA, 1991) is a worldview, a movement, in which all individuals are treated with dignity and respect, in which all are entitled to Everyday Lives.

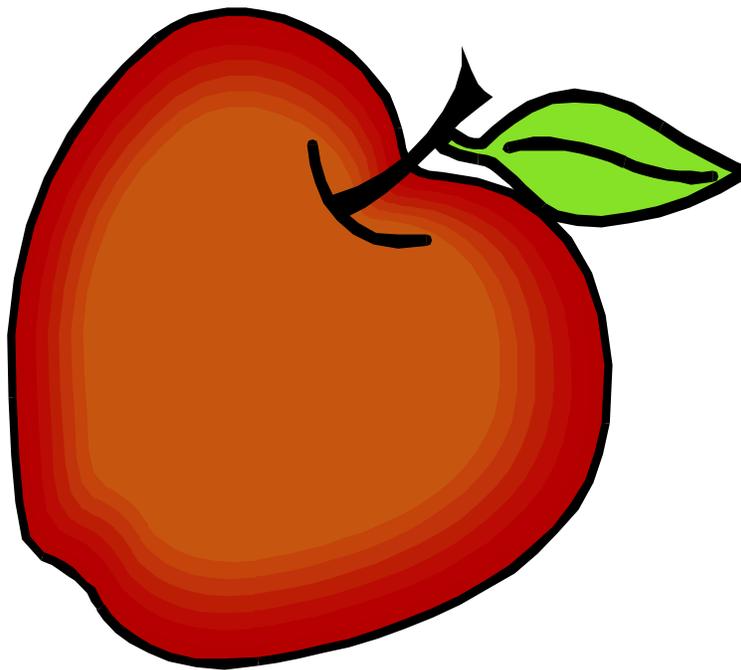
¹ Guy Legare, M.Ps., *Positive Approaches as a Paradigm*. Positive Approaches, "Identifying Mental Illness in People with Developmental Disabilities, Second Edition, OMR Statewide Training and Technical Assistance Initiative, PA, 2002.

- Positive Approaches requires getting to know each person, his or her unique qualities as well as his or her personal history.
- Positive Approaches requires that all people involved are comfortable enough to speak freely, that we all listen carefully and respectfully, that we take each person seriously, and finally, that we honor what we hear.
- Positive Approaches requires an examination of all aspects of the person's life including each person's living environment, relationships, activities and personal dreams.
- Positive Approaches is characterized by an integration of values, philosophies, and technologies. Its purpose is to support people to grow and develop, to make their own decisions, to achieve their personal goals, to develop relationships, and enjoy life as full members of the community.
- Positive Approaches encourages us to see clearly and honestly the good reasons and adaptive qualities of even the most troubling behavior, no matter whose it is.
- Positive Approaches is focused not on fixing the person, but on building competencies, creating opportunities and offering choices that help each person live a fulfilling life.
- Positive Approaches assumes that all behavior has meaning and that an individual's behavior can be a method to communicate needs and wants or the manifestation of some clinical issues.
- Positive Approaches provides viable alternatives and eliminates the need to rely on aversive and coercive methods.
- Positive Approaches measures success by the satisfaction of the person being supported.

OBSOLETE BULLETIN:

Mental Retardation Bulletin 00-91-05 entitled "Positive Approaches," issued February 8, 1991.

COMMUNITY HEALTH REVIEW



Philadelphia Coordinated Health Care

1601 Market Street, 5th Floor

Philadelphia, PA 19103

(215) or (888) 546-0300

www.pchc.pmhcc.org

AGENCY INFORMATION

AGENCY INFORMATION <i>(Agency Staff to complete pages 1 - 14 prior to performance of CHR)</i>	
Agency Name:	
Agency staff completing form:	
Telephone contact number:	
Position/Role:	
Date of agency form completion:	
DEMOGRAPHIC INFORMATION	
Name of Person to be Reviewed:	
Home address:	
Living Situation:	<input type="checkbox"/> CLA <input type="checkbox"/> ICF/MR <input type="checkbox"/> DOM CARE <input type="checkbox"/> BOARD <input type="checkbox"/> NURSING HOME <input type="checkbox"/> INDEPENDENT <input type="checkbox"/> FAMILY LIVING <input type="checkbox"/> With Family <input type="checkbox"/> Other:
County:	
Is there an Agency Nurse? <input type="checkbox"/> Yes <input type="checkbox"/> No	If Yes, Name:
Referral submitted by team involved in referral <i>(list all members)</i> :	
Family members involved: <i>(list names and relationship to individual being reviewed)</i>	
Name of Report "Point Person": <i>(person responsible for distribution of copies of the report to authorized individuals)</i>	
Mailing address of Report "Point Person":	
Summary of Request for Community Health Review <i>(Please summarize reasons that CHR has been requested)</i>	

OBJECTIVES

Objective(s) of *Community Health Review* What specific objective(s) are anticipated for the case manager, agency and individual? (For example: "Clarify health care supports needed since change in health status", "Clarify symptoms of mental illness", "Formulate questions for the physician to address current symptoms", "Determine the health care supports needed to enable the person to remain at home").

2.

2.

3.

4.

(Attach additional information, if necessary)

Race/Ethnicity (optional): Caucasian African-American Hispanic Asian Other:

Plaintiff Class Status: *(check all that apply)*

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> Pennhurst | <input type="checkbox"/> Other Litigation – describe: |
| <input type="checkbox"/> Embreeville | <input type="checkbox"/> Not a member of a plaintiff class |

Medical Insurance Coverage: *(check all that apply)*

- | | |
|--|---|
| <input type="checkbox"/> Americhoice | <input type="checkbox"/> Other – specify: |
| <input type="checkbox"/> HealthPartners | |
| <input type="checkbox"/> Keystone Mercy | |
| <input type="checkbox"/> Medicare | |
| <input type="checkbox"/> Medical Assistance (ACCESS) | <input type="checkbox"/> Other – specify: |
| <input type="checkbox"/> Blue Cross/Blue Shield | |

HISTORY AND SOCIAL SUMMARY

Date of Admission to Agency	
Admitted/transferred from? <i>(Where? i.e., agency, family home, etc.)</i>	
Date of Move to Current Address	
Number of Housemates	
Hours of Staff Support per Week	
Date of Birth:	
Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female
Level of Mental Retardation	<input type="checkbox"/> Borderline <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe <input type="checkbox"/> Profound
IQ Score & Date of Test	

Allergies & Sensitivities *(include reactions):*

Date of last Lifetime Medical History Summary Update: *(please attach a copy)*

Update Completed by: *(Name & Position)*

SCREENINGS AND IMMUNIZATIONS

SCREENING	DATE	RESULT
TB tine test		
TB Mantoux test		
Chest X-Ray		
Hepatitis B Antibodies		
Other <i>(describe)</i>		
IMMUNIZATION	DATE	RESULT
Tetanus/Diphtheria		
Hepatitis B		
Pneumovax		
Flu Vaccine		
Other <i>(describe)</i>		
Other <i>(describe)</i>		
Other <i>(describe)</i>		

PAST HEALTH HISTORY

SIGNIFICANT ILLNESS, INJURY, SURGERY	DATE	RESULT	DOCTOR/ SPECIALTY

PAIN ASSESSMENT*Issues Noted?* Yes No

Does this person have any condition(s) known to cause pain or that is/are *currently* causing this person pain?

 No Yes, if so, describe below:

Condition/Diagnosis	Pain Symptoms Described

Weight: (note *all* changes—*i.e.*, increase, decrease *with dates measured*.)

Height:

SPECIALTY THERAPIES:*Issues Noted?* Yes No

THERAPY TYPE <i>Please be sure to check "therapy type category"</i>	REASON	THERAPIST NAME	DATE OF LAST VISIT
<input type="checkbox"/> Physical			
<input type="checkbox"/> Occupational			
<input type="checkbox"/> Speech			
<input type="checkbox"/> Nutrition			
<input type="checkbox"/> Behavior			
<input type="checkbox"/> Other(1):			
<input type="checkbox"/> Other (2):			
<input type="checkbox"/> Other (3):			
<input type="checkbox"/> Other (4):			

BEHAVIORAL HEALTH ISSUES

BEHAVIORAL HEALTH – (CHECK ALL THAT APPLY)

- No behavioral health issues at this time
- This person has a behavior support plan in place
- There is a restrictive component to the behavior support plan
- The person has been restrained. *Frequency:* Over past **year** Over past **month** Over past **week**

- Data is being collected about this person's behavior
- A Behavior Specialist is involved. Name: _____
- Individual is taking psychotropic medication
- A Tardive Dyskinesia screening was done.

Date completed:

Results:

PSYCHOSOCIAL STRESSORS –(CHECK ALL THAT APPLY)

- Abuse physical sexual
- Behavioral concerns
- Changes in significant relationships (*family, friends, doctors, housemates*)
- Changes in work or day program
- Death of a significant person
- Mental Health diagnosis
- Move in residence/location
- Pain-related condition
- Substance abuse
- Trauma (define)

- Other** (*describe*)

DOES THE PERSON HAVE ANY OF THE FOLLOWING BEHAVIORS? *(If so, describe below the specifics of each behavior checked)*

- Aggression
- Anger
- Antisocial behavior
- Anxiety
- Appetite – increased
- Appetite – decreased
- Attention – decreased
- Biphasic course
- Bladder accidents
- Bowel accidents
- Changes in speech volume, quality, clarity, and rate
- Compulsions
- Confusion
- Decreased enjoyment/interest in pleasurable activities
- Delusions
- Destructive behaviors
- Discomfort (acute) in social settings
- Disorientation
- Distractible
- Fatigue
- Fearfulness
- Forgetfulness
- Hallucinations (describe:)
- Hyperactivity
- Impulsivity
- Increased crying and/or sadness
- Intense interest in pleasurable activities
- Increased laughing and smiling
- Increased self esteem or grandiosity
- Irritability

- Judgment errors
- Lack of empathy
- Limited interests
- Loss of language
- Loss of motor skills
- Non-compliance
- Obsessions
- Paranoia
- PICA
- Psychomotor agitation
- Rectal digging/smearing
- Ritualized or repetitive behaviors
- Rumination
- Screaming
- Self-injurious behavior
- Self-talk
- Sleep – decreased
- Sleep – increased
- Social avoidance
- Spitting
- Serious difficulties adjusting to change
- Stereotyped behavior (eg hand flapping)
- Suicidal ideation
- Thought disorders
- Vomiting (forced)
- Withdrawn
- Other** *(describe)*

- Other** *(describe)*

COMMENTS:

CURRENT PSYCHIATRIC DIAGNOSES

AXIS I	DIAGNOSIS	DESCRIBE SYMPTOMS
Psychiatric Disorders		
AXIS II	DIAGNOSIS	
Mental Retardation		
Personality Disorders		

Is there a substitute decision maker? Yes No

If "Yes", please indicate:

Name of substitute decision maker:
Relationship/Role:
Telephone Number(s):

Does the individual have an Advance Directive? Yes No

If "Yes", please indicate:

Who developed the Advance Directive:
Location of Advance Directive:

EMERGENCY VISITS

List all emergency room visits, medical and psychiatric hospitalizations in the past year:

HOSPITAL	DIAGNOSIS	OUTCOME

FAMILY HISTORY

Family Medical Conditions – Describe all, including cause(s) of death, *and note relationship to individual.*

Family Psychiatric Conditions – Describe all and *note relationship to individual.*

Printed name, signature of the person completing this section

Date _____

COMMUNITY HEALTH REVIEW

PCHC Nurse Section

Name of Individual Reviewed:	
PCHC Nurse Performing Review:	
Date of Review:	
Sources of information:	
Date of Review:	

Review all that has occurred in the past year. *Note any pertinent historical information.

Current System Review *(related to objectives and observations):*

GENERAL APPEARANCE – affect, posture, skin, hair, nails, weight, mood

COMMUNICATION *(Check all that apply)*

- Expresses thoughts and desires verbally
- Difficult to understand speech; speaks in phrases; generally able to communicate thoughts and desires
- Uses sign language or a language devices *(board, electronic, computer)*
- Uses gestures or sounds to communicate; thoughts/desires not clearly understood by others
- Communicates through use of photos, pictures or other visual aids
- Behavior, facial expressions, or body language are main form of communication
- Thoughts and desires not communicated. Those who know the individual are able to make pretty good guesses.

Instructions: Check boxes for “yes” and leave box blank for “no.” Describe “yes” or “no” when necessary in the space in the box. Are reports complete? Is there consistency of information through out the record (eg. Listed diagnoses)? Has there been follow up as recommended by the physician or specialist?

EARLY DEVELOPMENT

- Prenatal care:

- Labor and Delivery:

- Developmental Milestones:

- When was a delay first noticed:

- When was the individual diagnosed with mental retardation:

- Cause of mental retardation, if known:

- Childhood illnesses:

FAMILY INFORMATION

- Parent's names:

- Siblings names and ages:

- Approximate date individual left home: _____

- Describe the individual's life at home:*

SKIN, NAILS, HAIR*Issues Noted:* **Yes** **No****Color:****Integrity:**

- Requires positioning
- Edema
- Skin breakdown
- Skin infections
- Albumin Level
- Other:**

Date:**Result:****HEAD & NECK***Issues Noted:* **Yes** **No**

- Headaches
- Shunt
- Other:**

EYES*Issues Noted:* **Yes** **No**Last ophthalmology exam **date:**

- Glasses prescribed
- Wears glasses
- Myopia
- Strabismus
- Hyperopia
- Cataracts

- Glaucoma
- Other Vision Diagnosis:
- Other:**

EARS*Issues Noted:* **Yes** **No**

- Hearing loss – **Testing type:**
- Hearing Aid
- Hearing normal
- Impacted cerumen
- Infections
- Other:**

Date:**NOSE & SINUSES***Issues Noted:* **Yes** **No**

- Frequent colds
- Allergic rhinitis
- Nosebleeds
- Medications that cause stuffiness
- Other:**

DENTAL*Issues Noted:* Yes No**What kind of treatment over the past year** (*exam, cleaning, periodontal, etc*)?

- Has dentures
- Edentulous
- Difficulty chewing
- Requires sedation to see dentist
- Requires anesthesia for dental treatment
- Antibiotics required before dental appointment
- Other:**

Describe oral hygiene habits:**RESPIRATORY***Issues Noted:* Yes No

- Cough
- Asthma
- Pneumonia(s)
- Choking episodes
- Upper respiratory infections
- Mantoux - **Date:**
- Chest x-ray
- Other:**

Result:**CARDIOVASCULAR SYSTEM***Issues Noted:* Yes No

- High Blood Pressure – How often monitored?
- Mitral Valve Prolapse – Written documentation?
- Family history of heart disease
- EKG – **Date:** **Results:**
- Lipid Profile – **Results:**
- CBC/Differential – **Results:**
- Does this person smoke? Yes No
- Other:**

NUTRITION**Issues Noted:** Yes No**Current diet level?**

- | | |
|--|---|
| <input type="checkbox"/> Regular (no restrictions) | <input type="checkbox"/> Liquid |
| <input type="checkbox"/> Mechanical soft (chopped, ground) | <input type="checkbox"/> Tube Feeding (<i>G or J ?</i>) |
| <input type="checkbox"/> Pureed (all items) | <input type="checkbox"/> Other combination: |
| <input type="checkbox"/> Thickened | |

What is the current liquid level?

- | | |
|---|--|
| <input type="checkbox"/> Regular (thin) | <input type="checkbox"/> Honey |
| <input type="checkbox"/> Pudding | <input type="checkbox"/> Thickened |
| <input type="checkbox"/> Nectar | <input type="checkbox"/> Other: |

Is the diet and liquid level comparable with documented records?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

Does the individual have a special diet plan?

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Low calorie | <input type="checkbox"/> High calorie |
| <input type="checkbox"/> Low salt | <input type="checkbox"/> Carbohydrate controlled (no sugar) |
| <input type="checkbox"/> Low fat | <input type="checkbox"/> Other: |

Staff trained in meeting dietary needs? Yes No****If Yes, is documentation is present? Yes No*****Do staff need more information about meeting dietary needs? Yes No****How does the individual consume meals?**

- | | |
|--|--|
| <input type="checkbox"/> Independently | <input type="checkbox"/> Tube fed |
| <input type="checkbox"/> Minimal Assistance | <input type="checkbox"/> Uses adaptive equipment |
| <input type="checkbox"/> Total assistance required | <input type="checkbox"/> Has coughing episodes |

Staff trained in feeding technique? Yes No****If Yes, is documentation is present? Yes No*****If edentulous, can the person masticate current food types safely & without difficulty?**

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

Does this person have food allergies? Yes No***Describe:*****Does this person have food sensitivities? Yes No*****Describe:*****Is there a plan of support for nutritional/feeding issues? Yes No******If Yes, is documentation is present? Yes No***

GASTROINTESTINAL TRACT*Issues Noted:* Yes No

- Appetite
- Dysphagia
- How was dysphagia diagnosed? Videofluoroscopy? Table top eval? Other?
- GERD
- Liver condition
- Screened for Hepatitis
- Constipation – What is the bowel management plan?
- Diarrhea
- Bowel Obstruction
- Hernia
- Hemorrhoids
- Tested for H Pylori
- Liver Function Tests
- Hemocult

URINARY TRACT*Issues Noted:* Yes No

- Renal condition
- Urinary Tract Infections
- Incontinence
- BUN/Creatinine – **Results:** **Date:**
- Urinalysis – Results: **Date:**
- Other:**

GENITAL SYSTEM – FEMALE*Issues Noted:* Yes No

- Mammogram – **Date:**
- Self breast exams – how often? _____
- Breast exams performed by: Self Staff Nurse
- Menstrual cycle normal – If not, describe regularity, frequency, duration, dysmenorrhea:
- LMP
- Pap test – **Date:**
- Menopausal – note age of onset:
- Hormone replacement therapy has been considered
- Surgeries
- Other:**

GENITAL SYSTEM – MALE*Issues Noted:* Yes No

- PSA – **Results:** **Date:**
- Prostate exam – **Results:** **Date:**
- Self testicular exam – how often?
- Self testicular exams performed by: Self Staff Nurse
- Other:**

PERIPHERAL VASCULAR SYSTEM

Issues Noted: Yes No

- Extremities cold
- Doppler – Result:
- Edema
- Complaints of pain/cramps/numbness
- Varicosities
- Other:**

Date:

MUSCULOSKELETAL SYSTEM

Issues Noted: Yes No

- Osteoporosis
- Arthritis
- Cerebral Palsy
- Atlanto-axial instability
- Scoliosis – Type:
- Kyphosis
- History of fractures
- Other:**

Mobility status:

- Ambulatory
- Non-ambulatory
- Unsteady gait
- Adaptive equipment (wheelchair, braces, cane, walker, other):
- Range of motion

Ability to use adaptive equipment:

- Independent
- Needs assistance
- Dependent

Transfer:

- Independent
- Needs assistance
- Uses adaptive equipment

Routine Screen:

- Bone Density
- Receives supplements (calcium, vitamin D)

NERVOUS SYSTEM*Issues Noted:* Yes No

- Seizure Disorder
- Dementia
- Parkinson's Disease
- Tremors
- Movement disorders
- Dystonias
- EEG – **Results:**
- Other:**

Date:**HEMATOLOGIC SYSTEM***Issues Noted:* Yes No

- Anemia
- Bleeding
- Bruising pattern
- Other:**

ENDOCRINE SYSTEM*Issues Noted:* Yes No

- Thyroid
- Thyroid Function Test
- Diabetes
- Blood Sugar
- Other:**

Date:**Results:****Date:****Results:****OTHER PHYSICAL HEALTH CONCERNS***Issues Noted:* Yes No*Please describe:*

BEHAVIORAL HEALTH*Issues Noted:* Yes NoSee *Doctors List, Current Diagnoses,* and *Hospitalizations* list for relevant information.**Check all that apply:**

- None at this time
- Taking psychotropic medication *and* Tardive Dyskinesia screening was done.
Date last completed: _____ ***Results:*** _____
- If a psychotropic medication was discontinued, screening for Tardive Dyskinesia was continued.
For how many months? _____ ***months***
- This person has a behavior support plan
- There is a restrictive component
- The person has been restrained. In the past year Month Week
- Data is collected about the person's behavior
- A Behavior Specialist is involved. **Name:** _____
- Psychiatric diagnosis matches symptoms
- Medication matches the diagnosis and symptoms
- Behavior plan target symptoms match symptoms and diagnosis

PSYCHOSOCIAL STRESSORS*Issues Noted:* Yes No

- Abuse *physical* *sexual*
- Behavioral concerns
- Changes in significant relationships
- Changes in work or day program
- Death of a significant person
- Mental Health diagnosis
- Moving residence
- Pain related condition
- Substance abuse
- Trauma (*define*)
- Other.*** (*describe*)

OTHER BEHAVIORAL HEALTH CONCERNS*Issues Noted:* Yes No***Please describe:***

BEHAVIORS CHECKLIST

Issues Noted: Yes No

Does the person have the following behaviors? If so, describe specifics of behavior.
(Emboldened words are syndrome-specific symptoms.)

- | | |
|--|---|
| <input type="checkbox"/> Aggression | <input type="checkbox"/> Irritability |
| <input type="checkbox"/> Anger | <input type="checkbox"/> Judgement errors |
| <input type="checkbox"/> Antisocial behavior | <input type="checkbox"/> Lack of empathy |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Limited interests |
| <input type="checkbox"/> Appetite – increased | <input type="checkbox"/> Loss of language |
| <input type="checkbox"/> Appetite – decreased | <input type="checkbox"/> Loss of motor skills |
| <input type="checkbox"/> Attention – decreased | <input type="checkbox"/> Non-compliance |
| <input type="checkbox"/> Biphasic course | <input type="checkbox"/> Obsessions |
| <input type="checkbox"/> Bladder accidents | <input type="checkbox"/> Paranoia |
| <input type="checkbox"/> Bowel accidents | <input type="checkbox"/> PICA |
| <input type="checkbox"/> Changes in speech volume, quality, clarity, and rate | <input type="checkbox"/> Psychomotor agitation |
| <input type="checkbox"/> Compulsions | <input type="checkbox"/> Rectal digging/smearing |
| <input type="checkbox"/> Confusion | <input type="checkbox"/> Ritualized or repetitive behaviors |
| <input type="checkbox"/> Decreased enjoyment/interest in pleasurable activities | <input type="checkbox"/> Rumination |
| <input type="checkbox"/> Delusions | <input type="checkbox"/> Screaming |
| <input type="checkbox"/> Destructive behaviors | <input type="checkbox"/> Self-injurious behavior |
| <input type="checkbox"/> Discomfort (acute) in social settings | <input type="checkbox"/> Self-talk |
| <input type="checkbox"/> Disorientation | <input type="checkbox"/> Sleep – decreased |
| <input type="checkbox"/> Distractible | <input type="checkbox"/> Sleep – increased |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Social avoidance |
| <input type="checkbox"/> Fearfulness | <input type="checkbox"/> Spitting |
| <input type="checkbox"/> Forgetfulness | <input type="checkbox"/> Serious difficulties adjusting to change |
| <input type="checkbox"/> Hallucinations (describe:) | <input type="checkbox"/> Stereotyped behavior (<i>eg hand flapping</i>) |
| <input type="checkbox"/> Hyperactivity | <input type="checkbox"/> Suicidal ideation |
| <input type="checkbox"/> Impulsivity | <input type="checkbox"/> Thought disorders |
| <input type="checkbox"/> Increased crying and/or sadness | <input type="checkbox"/> Vomiting (<i>forced</i>) |
| <input type="checkbox"/> Intense interest in pleasurable activities | <input type="checkbox"/> Withdrawn |
| <input type="checkbox"/> Increased laughing and smiling | <input type="checkbox"/> Other (describe) |
| <input type="checkbox"/> Increased self esteem or grandiosity |
 |
| | <input type="checkbox"/> Other (describe) |

Describe the relationship between psychiatric issues, symptoms, symptoms, diagnoses, medications, medical conditions, psychosocial stressors, environmental stressors, and any other observations below:

FINDINGS SUMMARY

(List of concerns to be addressed & recommendations):

FINDING	RECOMMENDATION
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
11.	
12.	
13.	

COMMENTS:

Nurse Reviewer Name *(please print):*

Telephone:

Signature:

Date completed:

Developmental Programs Bulletins

Bulletin Number(s)	Program Office(s)	Subject/Title	Issue Date	Effective Date
<u>00-08-04</u>	ODP	Individual Eligibility for Medicaid Waiver Services	03/05/08	03/05/08
<u>00-08-03</u>	ODP	Procedures for Service Delivery Preference	01/30/08	01/01/08
<u>00-08-01</u>	ODP	Process for Qualification and Disqualification of Waiver Providers	12/27/07	01/01/08
<u>00-08-02</u>	ODP	Provider Profiles for Mental Retardation Providers	12/26/07	12/26/07
<u>4300-07-05</u>	ODP	Administrative Entity and Provider Contracts	08/17/07	07/01/07
<u>00-07-04</u>	ODP	Microboards(C)	07/01/07	07/01/07
<u>00-07-03</u>	ODP	Revised Service Definitions	05/01/07	07/01/07
<u>00-07-01</u>	ODP	Provider Billing Documentation Requirements for Waiver Services	04/26/07	04/26/07
<u>00-07-02</u>	ODP	Overview of the Supports Intensity Scale(C) (SIS(C)) and the PA Plus	04/26/07	04/26/07
<u>00-06-16</u>	ODP	Approved Consolidated Waiver	12/28/06	12/23/06
<u>00-06-15</u>	ODP	Prioritization of Urgency of Need for Services (PUNS) Manual	12/22/06	12/22/06
<u>00-06-14</u>	ODP	Office of Mental Retardation Provider Dispute Resolution Protocol	12/11/06	07/01/06
<u>00-06-13</u>	ODP	Service Review Protocol for Individuals in the Consolidated and Person Family Directed Support Waivers	09/07/06	07/01/06
<u>00-06-12</u>	ODP	2006-2007 Person/Family Directed Support Waiver Cap	08/08/06	08/08/06
<u>00-06-11</u>	ODP	Provider and County Incident Management	06/23/06	06/23/06

		Analysis Report		
00-06-10	ODP	Payment for Sign Language Interpreters and/or Translitterators	05/10/06	05/10/06
00-06-09	ODP	Elimination of Restraints through Positive Practices	05/01/06	05/01/06
00-06-08	ODP	Employment for Individuals in ICFs/MR	04/05/06	04/05/06
00-06-07	ODP	Provider Qualification Pilot Program	04/05/06	04/05/06
00-06-06	ODP	Interim Rate Setting Procedures For FY 2006/2007	03/08/06	03/08/06
00-06-05	ODP	County to County Relocations	02/24/06	02/24/06
00-06-04	ODP	Revised Units for Service Definitions and Procedure Codes for Healthcare and Non-Healthcare Waiver and Base Services	01/31/06	07/01/06
00-06-03	ODP	Payment for Sign Language Interpreters	01/25/06	01/25/06
00-06-02	ODP	Office of Mental Retardation Provider Dispute Resolution Protocol for Individuals in the Consolidated Waiver	01/20/06	10/01/05
00-06-01	ODP	Home & Community Based Service Eligibility/Ineligibility/Change Form	01/03/06	01/03/06
00-05-07	ODP	Office of Mental Retardation Policy on Employment	12/20/05	12/20/05
00-05-06	ODP	Office of Mental Retardation Service Review Protocol for Individuals in the Consolidated Waiver	12/16/05	10/01/05
00-05-05	ODP	2005-2006 Person/Family Directed Support Waiver Cap	10/18/05	10/18/05
OMHSAS-05-01	OMHSAS, ODP	Cost Settlement Policy and Procedures for Community-Based Medicaid Initiatives	08/15/05	07/01/04
00-05-04	ODP	Lifesharing through Family Living	08/08/05	08/08/05

00-05-03	ODP	Services Requiring Third Party Insurance Review Prior To Consideration For Waiver Payment	07/05/05	07/05/05
00-05-02	ODP	P/FDS Waiver Amendment to Allow for the Provision of Respite Services in Contiguous States	05/31/05	05/31/05
00-04-14	ODP	Determining Medical Assistance Eligibility for Families of Infants and Toddlers Who Apply for Supports and Services Authorized by a County Mental Health/Mental Retardation Program	01/28/05	01/28/05
00-04-15	ODP, OMAP	Alternative Sanction Guidelines for ICF/MR Medical Assistance Certification	01/28/05	01/28/05
00-04-13	ODP, OMHSAS	Limited English Proficiency (LEP)	01/20/05	01/20/05
00-05-01	ODP	Issuance of Audit Guide for Non-State Operated Intermediate Care Facilities for the Mentally Retarded.	11/30/04	11/30/04
00-04-12	ODP	Clarifying the '30-Hour Rule'	10/08/04	10/08/04
00-04-11	ODP	Certified Investigations	09/16/04	09/16/04
OMHSAS-04-01	OMHSAS, ODP	Cost Settlement Policy and Procedures for Community-Based Medicaid Initiatives	09/09/04	07/01/03
00-04-10	ODP	Service Definitions and Procedure Codes for Healthcare Waiver and Base Services	09/03/04	09/03/04
00-04-02	OCYF, OMHSAS, ODP	MH/MR Services for Children Placed Out-of-County in Pre-Adoptive or Foster Homes	07/19/04	08/20/04
00-04-08	ODP	Determining Medical Assistance Eligibility for Individuals Age Three and Older Who Apply for Supports and Services	05/10/04	05/10/04

		Authorized by a County Mental Health/Mental Retardation Program		
00-04-07	ODP	Clarifying Procedures for Individual and Provider Appeals	03/15/04	03/15/04
99-04-06	OMAP, ODP, OSP	Home and Community Based Waiver Provider's Billing of HIPAA Compliant National Codes Based on Authorized Plans of Care Through the Home and Community Services Information System and PROMISe	03/10/04	03/01/04
6000-04-01	ODP	Incident Management	02/18/04	02/28/04
00-04-06	ODP	Revised Cost Centers	02/06/04	07/01/04
00-04-05	ODP	Positive Approaches	01/09/04	01/09/04
00-04-01	ODP	Intermediary Service Organizations (ISOs)	01/02/04	01/02/04
00-04-03	ODP	Procedure Codes for Early Intervention Waiver Services FY 2003-2004 Early Intervention Services FY 2003-2004	01/02/04	03/01/04
00-04-02	ODP	Procedure Codes for Medical Assistance Early Intervention Services FY 2003-2004	01/02/04	03/01/04
00-04-04	ODP	Procedure Codes for Early Intervention Base Services FY 2003-2004	01/02/04	03/01/04
00-03-12	ODP	Service Definitions and Procedure Codes for Healthcare and Non-Healthcare Waiver and Base Services	12/31/03	03/01/04
00-03-11	ODP	Medical Assistance for Workers with Disabilities In the Community Mental Retardation Program	11/25/03	11/25/03
00-03-10	ODP	Payments for Psychological Testing to Diagnose Mental Retardation in Children and	10/21/03	10/21/03

		Adults		
00-03-09	ODP	Clarifying the '30 Hour Rule'	09/25/03	09/25/03
00-03-08	ODP	Procedures Codes for Electronic Transfers of Health Care Services	08/13/03	10/16/03
00-03-07	ODP	Medication Administration Training Program	08/12/03	08/12/03
00-03-06	ODP	FY 2001/2002 Utilization, Statistical and Financial Report	07/28/03	07/28/03
00-03-05	ODP	Principles for the Mental Retardation System	06/13/03	06/13/03
00-03-04	ODP	OBRA Time-Limited Determinations	05/13/03	05/13/03
00-03-03	ODP	Clarifying Waiver Funding and Domiciliary Care Payments	03/04/03	03/04/03
00-03-02	ODP, OMHSAS, OSP, OCYF	Site Visits and Access by Pennsylvania Protection and Advocacy, Inc.	02/19/03	02/19/03
00-03-01	ODP	Passage of Act 171 relating to the Older Adults Protective Services Act (OAPSA)	02/11/03	02/11/03
00-02-16	OMHSAS, ODP	Coordination of treatment and support for people with a diagnosis of serious mental illness who also have a diagnosis of mental retardation	12/17/02	12/17/02
00-02-13	ODP	Need for ICF/MR Level of Care	08/07/02	08/07/02
00-02-12	ODP	Person/Family Directed Support Waiver Renewal	08/06/02	08/06/02
OMHSAS-02-03	OMHSAS, ODP	Cost Settlement Policy and Procedures for Community-Based Medicaid Initiatives.	07/18/02	07/01/01
00-02-09	ODP	Pro Re Nata Medication Usage For Psychiatric Treatment - Clarification Of Interpretation	07/11/02	07/11/02
OMHSAS-02-02	OMHSAS, OMAP,	Performance Expectations and Recommended	06/06/02	06/06/02

	OCYF, ODP	Guidelines for the County Child and Adolescent Service System Program (CASSP)		
4210-02-05	ODP	Clarifying Eligibility for Mental Retardation Services and Supports	05/31/02	05/31/02
00-02-10	ODP	Foster Care Tax Reform as it relates to the Lifesharing/Family Living program	05/20/02	05/20/02
00-02-07	ODP	Accessing Public Transportation for Individuals Enrolled in the Consolidated or Person/Family Directed Support Waivers	04/15/02	04/15/02
00-02-06	ODP	Revision of Definition of Conflict Free Providers for Targeted Service Management	04/12/02	04/12/02
00-01-05A	ODP	Statements Of Policy - Incident Management [55 PA. Code CH. 6000]	03/28/02	03/28/02
00-02-04	ODP	Principles for the Mental Retardation System	03/25/02	03/25/02
00-02-03	ODP	Office of Mental Retardation's Monitoring of Counties	03/05/02	03/05/02
00-02-01	ODP	Medicaid Waiver for Infants, Toddlers and Families Renewal	01/29/02	07/01/01
00-01-07	ODP	Announcement: Step-By-Step Guide to Ready Providers for the Reporting of Incidents through HCCIS	12/17/01	12/17/01
00-01-06	ODP	Announcement of Certified Investigator Training	09/06/01	09/06/01
00-01-04	ODP	Person/Family Directed Support Waiver Amendment	08/21/01	08/21/01
00-01-02	ODP	Approved Consolidated Waiver	06/08/01	07/01/01
OMHSAS-00-04	OMHSAS, ODP	The Roles and Responsibilities of County	10/04/00	10/04/00

		Mental Health/Mental Retardation Programs in the Development of a Child's Individual Education Program		
00-00-10	ODP	Reorganization of the Office Mental Retardation	08/11/00	08/11/00
00-00-09	ODP	Service Preference in Medicaid Waivers for Individuals with Mental Retardation	08/04/00	11/01/00
00-00-04	OMHSAS, ODP	Guidelines for Identifying Persons with Mental Retardation and Mental Illness for State Mental Health Hospital Discharge	05/15/00	05/15/00
OMHSAS-03-02	OMHSAS, ODP	Cost Settlement Policy and Procedures for Community-Based Medicaid Initiatives.	08/01/98	08/01/98
00-98-07	ODP	Eligibility and Freedom of Choice in Medicaid Waiver for Infants, Toddlers and Families	07/01/98	07/01/98
SMH-96-01	OMHSAS, ODP	Tuberculosis Infection Control Program.	08/09/96	08/09/96
OMH-94-10	OMHSAS, ODP	Account Structure Manual - Revised Cost Centers for County Mental Health and Mental Retardation Programs	06/24/94	07/01/94
SMH-93-03	OMHSAS, ODP	Tuberculosis Surveillance and Management.	09/21/93	09/21/93
00-93-23	ODP, OMHSAS, OIM	Medical Assistance for Children	09/15/93	09/15/93
SMH-93-04	OMHSAS, ODP	Immunization of Patients/Residents and Employees.	07/09/93	08/01/93
OMH-91-13	OMHSAS, ODP	Mental Health/Mental Retardation Annual Income and Expenditure Reports	10/21/91	07/01/91
00-89-17	ODP	Abatement for Liability For Psychological Evaluations	09/14/89	09/14/89
00-88-07	ODP	Obtaining Criminal	06/24/88	06/24/88

		Clearances On Prospective Employees		
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* Indicates that the bulletin has become obsolete. **Note:** The details and text of the bulletin document are still available for viewing.

A watercolor illustration of a neighborhood. In the foreground, there is a white picket fence. Behind it, several houses with different colored roofs (red, blue, yellow) and walls are visible. The style is soft and artistic, with visible brushstrokes and a slightly blurred background.

Everyday Lives

Making It Happen

Pennsylvania Department of Public Welfare
Office of Mental Retardation

Message

We are pleased to present *Everyday Lives: Making It Happen*. This is an updated version of the original *Everyday Lives* booklet that was an expression of the concept of people having a life like other people in the community. Since the concept has been the framework for the system for ten years, The Planning Advisory Committee to the Office of Mental Retardation believed this to be an appropriate time to evaluate whether people's lives have changed. The Planning Advisory Committee is pleased to report that progress has been made, and we support this updated vision statement.

At our request, the Self-Determination Consumer and Family Group agreed to take on this project that included evaluating what has changed since ten years ago, what challenges remain, and how do we make the vision of an Everyday Life for everyone, a reality. Thank you for a job well done. We would also like to thank Evelyn Wermuth for providing guidance with the project and writing this booklet.

*Sheila Stasko and Nathaniel J. Williams,
Co-Chairpersons
Planning Advisory Committee*

Pennsylvania Self-Determination Consumer and Family Group Members

Donald Angermier , Blair County	Susan Fay McCloskey , Mercer County
Rosemarie Appel , Westmoreland County	Kim McMillian , Warren County
Mooneen P. Bielecki , Luzerne County	Suzanne Miller , Cambria County
Kathy Brill , Dauphin County	Bonnie Miller , Franklin County
Janet A. Brouse , Schuylkill County	Melissa A. Morgan , Butler County
Peter Buhr , Lancaster County	Carolyn Morgan , Philadelphia County
Sherry Byrne , Cumberland County	Jack Morrone , Lehigh County
Dee Coccia , Philadelphia County	Nancy Murray , Allegheny County
Wanda Davis , Blair County	Toni E. Newcomer , Westmoreland County
Maureen A. Devaney , Philadelphia County	Nancy Norwood , Franklin County
Oscar Drummond , Philadelphia County	Mary Ohl , Pike County
Marielynn Fairman , Jefferson County	Kim T. Rhodes , Clarion County
Brenda Folk , Bedford County	Sue Scott Dolan , Dauphin County
Kim Garretson , Somerset County	Kathy L. Smith , Erie County
Pedro Geraldino , Montgomery County	Julie Ann Smyser , Cumberland County
Dana Hughes , Fayette County	Sheila Stasko , Lehigh County
Laurie Kohler , Cumberland County	Evelyn Wermuth , Lancaster County
Debbie Leasure , Crawford County	Oscar Vargas , Philadelphia County
Teddi W. Leiden , Blair County	Marybeth Zahorchak , Butler County
Leah C. Leiden , Blair County	

Introduction

Ten years ago the concept of having an “everyday life” was explored and expressed in the first Everyday Lives booklet. Since then, Everyday Lives concepts have provided the framework for the Multi-Year Plan, the Plan to Address Pennsylvania’s Waiting List and system changes to support self-determination.

The Pennsylvania Self-Determination Consumer and Family Group was asked, by the Planning Advisory Committee to the Office of Mental Retardation, to review how lives have changed from ten years ago and create an updated booklet called *Everyday Lives: Making It Happen*. The Group is comprised of self-advocates and families from across the state. The following questions have guided the task:

- Have we made progress towards people having Everyday Lives?
- What is life like now for people with mental retardation and their families?
- What still needs to be done?
- How do we move forward?

The concept of Self-Determination has spread throughout the nation in recent years and it is the basis for people having everyday lives. An everyday life is having a life that is typical of the general population. Self-Determination is not just for a limited group of people. It is for *everyone* including children, young adults and older adults whether they need a lot of support or they can live on their own. It means having friends to play with as children, having jobs and serving in their churches as adults, and choosing how to spend their time in retirement. Individuals and their families want to have everyday lives. Parents, who are providing care for their sons or daughters with disabilities, often do not have the opportunity to do ordinary things that other people in society take for granted such as going to the movies or out for dinner together and attending community or school meetings. As the person with a disability grows older, his or her life and consequently the life of the family do not follow the typical path. In our society, children typically grow up to become independent and then move out of their family’s home. But as many individuals with mental retardation age, they continue to live in their family’s home relying on their aging parents and siblings for support.

History

1940's

Families across the Commonwealth formalized their support and advocacy network with the incorporation of the Pennsylvania Association for Retarded and Handicapped Children, 1949

1960's

The Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L.88-164) provided money to build community facilities, 1963

Social Security Act Amendments (P.L. 88-97) established Medicare and Medicaid, 1965

The Pennsylvania MH/MR Act established a system of community services, 1966

1970's

Right to education with right of due process was established in PA as result of PARC vs. Commonwealth of Pennsylvania, 1971

Family Support Services (FSS) funded for the first time, 1971

Community Living Arrangements (CLA) funded for the first time in Pennsylvania, 1971

The Federal Education for All Handicapped Children Act (94-142) mandated free, appropriate and individualized education for all children in the least restrictive environment, 1975

Protection and Advocacy system mandated (P.L. 94-103), 1975

Federal Court rules that institutionalization is a violation of constitutional rights to equal protection in the case of PARC vs. The Pennhurst State School and Hospital, 1977

1980's

Self Advocates in Pennsylvania formalize their peer support group and incorporate as Speaking for Ourselves, 1982

Fair Housing Act, 1988

Family Driven Support Services (FDSS) begin

Office of Mental Retardation, Planning Advisory Committee originated, 1988

1990

Americans with Disabilities Act (ADA)

Early Intervention Services System Act, Governor Robert P. Casey

1991

Everyday Lives, Governor Robert P. Casey

1992

The Arc-Pennsylvania became new name for the Association for Retarded Citizens, in response to self advocates' criticism of the use of the word retarded

1997

A Multi-year Plan for Pennsylvania's Mental Retardation Service System, The Planning Advisory Committee to the Office of Mental Retardation

1998

Waiting List Campaign: Individuals and families advocate for services for people and families who have been waiting for a long time

Governor Thomas J. Ridge Five Year Plan to Address the Waiting List, 1998; commits \$850M to expand services for those waiting

1999

Pennsylvania Self-Determination Steering Committee as subgroup of the Planning Advisory Committee begins

A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania, Planning Advisory Committee to the Office of Mental Retardation

Self-Determination in services made possible through a grant from the Robert Wood Johnson Foundation and implementation of the Person/Family Directed Support Waiver

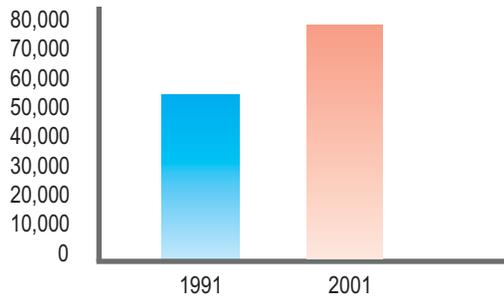
2001

Governor Thomas J. Ridge Direct Service Professionals Initiative; allocation of about \$22M to help providers recruit and retain the workforce needed to assure quality services

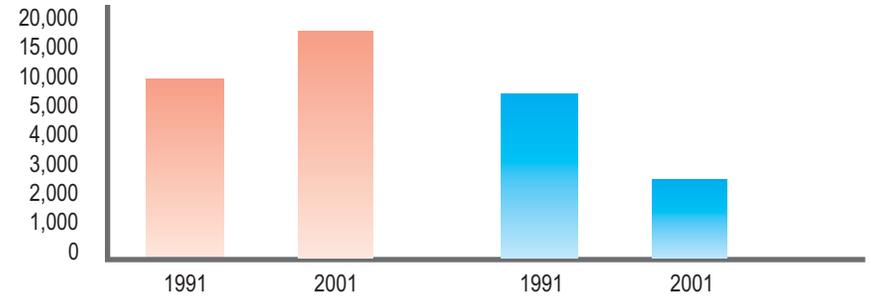


Life at This Time

There are many things in the mental retardation system that have changed over the past ten years. Following are some graphs to show the changes:

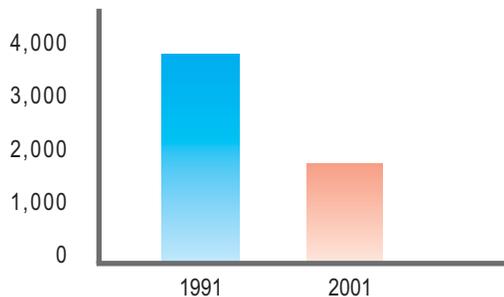


People Receiving Supports and Services
55,300 (1991) – 77,616 (2001)

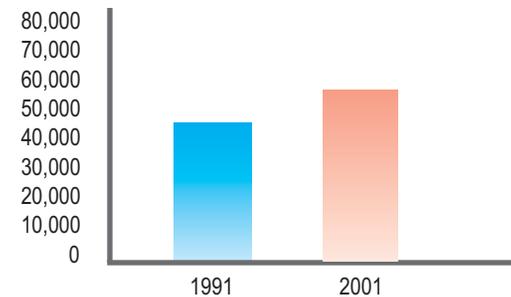


People Living in Community Settings

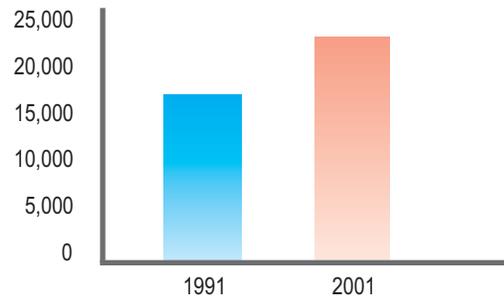
Small Settings 8,776 (1991) Includes ICF's/MR – 16,022 (2001)
Large Settings 5,479 (1991) Includes private ICF's/MR – 2,146 (2001)



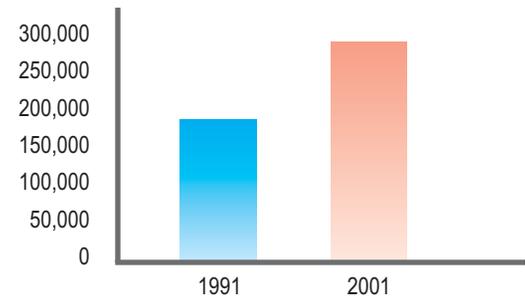
People in Public Institutions
3,900 (1991) – 1,700 (2001)



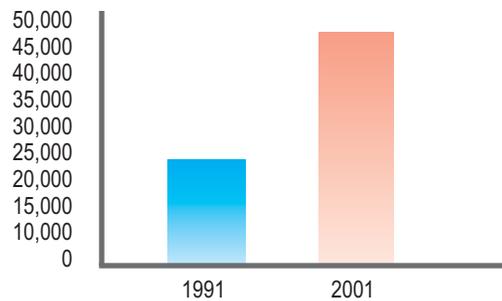
People Living at Home Receiving Services
43,000 (1991) Includes employment and day services – 57,730 (2001)



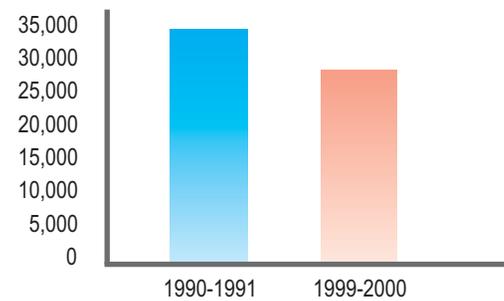
Families Receiving Family Support Services/In-home Waiver Services
15,800 (1991) – 23,261(2001)



Children Age 6-21 in Special Education Classes
193,000 (1991) – 298,524 (2001)

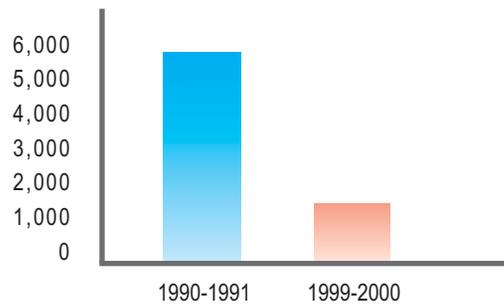


Children Birth to School Age Receiving Early Intervention Services
24,000 (1991) –
47,000 [18,000 birth to 3; 29,000 age 3 to school age] (2001)

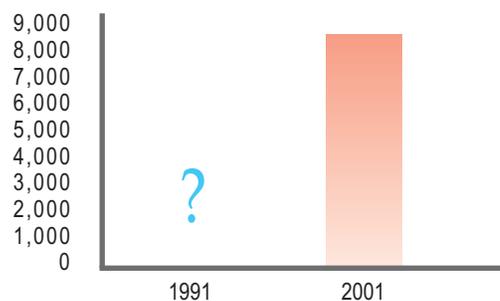


Children Age 6-21 in Special Education Classes With Mental Retardation
34,380 (1990-1991) – 27,547 (1999-2000)

Life at This Time, continued



Children Age 6-21 in Special Education Classes In Segregated Placements
5,801(1990-1991) – 1,391 (1999-2000)



People Waiting for Services

The number was not known in 1991.

An estimated equal number of people emerge every year; this is sometimes called the "Shadow List." – 8,320 (2001)

Where People Live

- More people are living in the community now rather than in institutions.
- Most people live with their families. Many are living with their aging parents. Some live with siblings or other relatives.
- Some people live in a family living situation in which an individual is matched with a family so they can share their lives.
- Some people rent their own apartments or own their homes.
- Some people live in houses or apartments operated by an agency in the community.
- Some people live alone and some people share their home with other people.
- Some people choose where they live and the people who share their home.
- Some people live in private schools and institutions, nursing homes and personal care boarding homes; others are in hospitals and jails.

And 1,700 still live in state funded institutions and approximately 1,760 live in large private institutions.

Education

- Nearly 96% of children eligible for early intervention services birth to age 3 receive early intervention services at home or in the community.
- Other young children are in Head Start, day care, community or segregated pre-school programs.
- Over 27,000 school-aged children with mental retardation are enrolled in special education classes, many in segregated environments.
- Some children are in regular classes in their neighborhood public school and have opportunities to interact with their peers.
- Some children are attending private schools.
- Children have several transitions in their lives. At age 3, they leave the Public Welfare early intervention system and transition to pre-school early intervention. At age 5 or 6, they enter the public school system. Some children choose to stay in school until age 21 and others leave school at age eighteen. Some schools have individualized work experience programs to prepare students for life after graduation.
- Some people go to technical schools after leaving high school.
- A few adults audit courses at community colleges.
- Some adults graduate from a community college with an Associate Degree.

Most young adults do not have the opportunity to continue their education after they leave high school.



Life at This Time, continued

Paid Employment and Daily Activities

- Some people get jobs on their own or through county programs. They work at different kinds of jobs. Some people work outdoors, others work in offices or stores.
- 9,570 people have obtained jobs through supported employment programs.
- 16,442 people attend day care centers or work activity centers.
- Some people are contributing to their communities through volunteering.
- Some older adults have individualized retirement supports.
- Some older adults choose to participate in generic community senior services.
- Many people are struggling to find things, that are important to them, to do every day.

Many people have nothing to do during the day.

Recreation and Leisure Activities

- More people are participating in community recreation. Children are involved with religious youth groups, Little League, play-ground activities, Scouting programs, 4-H, dancing and after school activities. Adults go mall walking, join baseball teams, bowl in community leagues, go horseback riding, shop, go dancing, go out with friends to local restaurants and bars, visit friends, are members of religious/spiritual groups, participate in community senior activities and work on crafts and hobbies.
- Some recreation is individualized with individuals choosing to attend an exercise class or use a community swimming pool or fitness club.
- Some people have memberships in the public library, local service clubs, and senior groups including travel groups.
- Some people have subscriptions to magazines related to their interests.
- Some people have driver's licenses.
- Some people plan for and take vacations.
- Dating is difficult and sometimes discouraged; however, some people do date, get married and have children of their own.

Most recreation opportunities are still segregated and group structured rather than individualized.

Transportation

- Transportation remains a big challenge for people. Public transportation is not available in rural areas. Where available, accessible transportation may not operate when individuals need to go to work, to medical appointments or to recreational events.
- Often adequate and affordable transportation is not available or is not accessible.
- Agency provided transportation is generally tied to segregated programs.
- Some counties provide paratransit services.
- When transportation is available, sometimes the cost is prohibitive.
- Some transportation services are starting to become available through the mental retardation system and other service systems such as aging.

Parents and family members still provide most of the transportation for people, regardless of their age.



Real Lives

People are beginning to have lives that are similar to that of other people who do not have disabilities. They have more control over their lives and have the opportunity to make choices in their lives. This is happening even for people who at one time had no way to express their wishes.

- Some people know how much money is spent on the supports and services they need.
- Some people have control over how the money in their budget is spent.
- Some people have individual plans, created with help from people they choose, that include what they need in order to have the kind of life they want.

Lynda Jane: Self-Determination

Lynda Jane is 35 years old. She lived at home with her family until she was 18 when she moved to a community home in Lancaster, Pennsylvania. Lynda Jane needs assistance with everyday activities; she does not speak and she has an uncontrollable seizure disorder.

Lynda Jane attended a facility based day training program for many years after she finished school at age 21. She wasn't interested in some of the activities and the ones she enjoyed at first (assembling things) she eventually became bored with and would take apart what she had assembled. Lynda Jane then was given the opportunity to do volunteer work in the community, with staff assistance, for two days a week. This later was expanded to five days a week. One job is folding towels and wash cloths at a nursing home. One of the residents has become Lynda Jane's friend and comes to see Lynda Jane each week when she is

there. By volunteering at different places during the week, Lynda Jane gets to be with many more people in the community and she is much happier now.

Throughout her life various kinds of communication aids had been tried with no success. The people working with Lynda Jane pay attention to her body language and have developed good relationships with her. About a year ago her supervisor got a programmable communication pod (device) to try with Lynda Jane. It has a bright top that you press to activate it. Lynda Jane loves the ceiling fan in her living room and would look at it when she wanted someone to turn it on. The device was programmed to say, "Please turn on the fan." It didn't take Lynda Jane very long to learn that if she would press the pod, then the fan would be turned on. A second pod with a different colored top was added a while later. This one is used in the van

she rides on the way to her volunteer activities. Lynda Jane loves brochures and knew they were kept in the glove compartment for her. This new pod says, "Please give me my brochures." Recently a third pod has been added that says, "Please come and talk with me." People who support Lynda Jane always respond promptly when Lynda Jane presses a pod. For the first time in her life, Lynda Jane has a voice.

Lynda Jane in recent years has also been given the opportunity to make choices in her life. Lynda Jane has long pretty hair and often wears part of it in a ponytail. She goes shopping with people who support her to pick out hair accessories and chooses the one she wants for the day by picking it up. Next they worked on Lynda Jane choosing blouses. They put several on her bed and she looks at the one she wants to wear and ignores the ones she doesn't want. After a while, they

added slacks that she chooses the same way. Recently the supervisor has begun to ask the three ladies in the house if they want to hire people who are interviewed to work there. After a person who was interviewed leaves the house, the supervisor asks Lynda Jane, "Do you want to give (person's name) a chance?" If Lynda Jane looks directly at the supervisor, the answer is yes. If she looks away, the answer is no. Just to be sure, the supervisor goes through the same procedure about five minutes later. Lynda Jane now has a voice and is able to make choices in her life including the people who work with her. Lynda Jane has an individual plan and the people who are paid to support Lynda Jane work together with her parents as a team. The team discusses ways to expand Lynda Jane's opportunities for choice and ways to expand her communication when they meet.



Real Lives, continued

MichaelAnn . . . Communicating in Her Own Way

MichaelAnn is four years old and lives at home with her mom, dad, and their dog, Webster. Her dad says, "She has a smile that melts away a tough day at work, and a determination that inspires you." MichaelAnn cannot talk and needs almost total assistance with her daily living activities.

MichaelAnn loves telling people around her what she wants and sometimes can be very demanding if she wants something right now. She does not speak and has her own unique way of communicating. She communicates through her body language, sounds and eye gaze. People need to spend some time with her before they can understand what she is saying.

MichaelAnn's parents have seen improvements since she has been attending pre-school and they feel the teachers and therapists are doing a wonderful job. One of the tools to help teachers, aides, and others who work with MichaelAnn is her individual plan. This document is a collaborative effort of people involved in MichaelAnn's life and it helps people who work with her know how to best understand and support MichaelAnn. The sections called, "How MichaelAnn

Communicates" and "What People Need to Know and Do to Support MichaelAnn" have helped to give her a voice.

MichaelAnn received a musical "Sit and Spin" toy from Santa but because of some motor planning problems she is not able to play on it without assistance. In learning MichaelAnn's language, her parents know that if she stands by it or paces back and forth to it, she wants to play on it. They help her onto it and assist her in spinning. MichaelAnn shows her enjoyment through laughter. After a few months of doing this, sometimes when her parents started spinning her, she would get fussy. Her parents had to figure out what MichaelAnn was saying. They learned that if MichaelAnn didn't keep her legs crossed on the "Sit and Spin," then she just wanted to sit on it and play the music.

MichaelAnn didn't laugh very much before her parents took the time to understand her communication. Her mom says, "Learning MichaelAnn's language and sharing it with others in her life has made my daughter blossom. She participates in her life more and is happier."

Jeremy “ We work as a team. They help me and I help them.”

Jeremy lives in a rural area with his Mom, Dad, sister, niece and nephew. At home Jeremy puts his clean clothes away (his sister does the laundry), cleans and dusts his room, takes out the trash, unloads the dishwasher, and feeds and waters the chickens. He also gathers the eggs. In the winter he helps bring in wood using his four-wheeler.

Jeremy graduated from high school in 1997 and then had a summer job. When that job was finished, he began work at the Seton Corporation in Saxton, Pennsylvania where leather car seats are made. Jeremy works five days a week. Jeremy had a job coach with him until he learned his job. Now his coach only sees him once in a while to see how he is doing. His Mom takes him to work at 6 a.m. and his sister picks him up after work at 2 p.m. Sometimes he rides home with one of his friends. Jeremy goes out to eat breakfast or lunch with his friends from work. Sometimes they go boating, attend ice hockey games, go bowling and go shopping. He has a lot of friends at work. As Jeremy says, “We work as a team. They help me and I help them.”

Jeremy regularly is involved in community activities. He either walks or rides his four-wheeler to town to participate in activities. Jeremy enjoys visiting the Fire Hall where he sometimes has dinner and helps with Bingo or washing the fire equipment with the men. He also enjoys helping with town sales and enjoys buying tools for his shed and fruit for his Mom. Dances are held in town on Friday evenings and Jeremy enjoys going dancing.



Real Lives, *continued*

Alexa Makes the World a Better Place

Alexa's parents have always wanted her to be fully included in school and in the community. Although Alexa is only twelve years old, her parents have been focusing on her future as an adult. They want her to have the know-how and confidence to be able to make good decisions about her own life and the supports she may need in the future. In order to make those decisions many skills need to be learned. Alexa needs to have good communication about her wants and needs and good relationship-building and problem-solving skills.

Alexa's parents believe that being overly protective of Alexa or giving undue attention to her will not contribute to her independence. As difficult as it was at times to overcome obstacles they faced, her parents felt it was necessary to persevere. They worked to convince communities, schools, friends and relatives that they want the same things for Alexa as they want for her two sisters, and they all need to treat Alexa no differently.

The persistence and vision of her parents have paid off and Alexa truly is part of her community. The regular school bus is equipped

with a wheelchair lift so Alexa can ride to her neighborhood school with her friends and neighbors; Alexa goes to regular physical education classes rather than adapted ones; and Alexa gets phone calls from friends asking if she is going to school dances. The neighborhood children use duct tape to attach a street hockey stick to Alexa's power wheelchair so she can play the game with them in the evening. The people from a local clothing store apologized for not having accessible floor space for Alexa and promptly corrected the situation. Her mom says, "All of these instances have not only helped to assist in reaching Alexa's goals and visions for the future, but they also help to change attitudes about the realities and capabilities of people with disabilities. As parents, professionals, community members and friends all work together to ensure that our world is a welcome place for ALL people, we will invariably prove to ourselves that for every obstacle we face, we can indeed find solutions. Alexa feels very comfortable in her school and community."

Amy Enjoying the Community

Amy is 33 years old and lives with her family in a suburb of Pittsburgh. Her family saw a change in her personality when she was 15 years old and she was diagnosed with depression with psychosis when she was 19. She also has hyper-sensitive hearing and crowds make her anxious. Periodically she has had episodes of depression that have prevented her from enjoying the life she had previously. When Amy was about 18 years old, she left school because she couldn't handle the stress. She received home schooling and worked mornings at the school assisting the maintenance staff with cleaning classrooms until she was 21 years old.

When her high school education was completed, Amy was on a waiting list to receive day services. Funding became available after six months of waiting and Amy then attended a day program five days a week. She was in an environment where she was able to help other people and this helped to elevate her self-esteem. After participation in this program for five years, Amy decided that she wanted to get a job. First she did volunteer work for one year

and then she obtained a paying job at a convent where she did various kitchen jobs and fixed trays for nuns who were in the infirmary. Amy worked at this part-time job five days a week. When she wasn't working, Amy did jobs around the house and relaxed. She was capable of staying alone at this time. Amy was able to use public transportation and do things she enjoyed in the community such as bowling and going out to eat in restaurants with friends.

Things changed and Amy's life became limited by her mental illness and once again she was on a waiting list for supports. Amy has a person-centered plan and a circle of friends who are not paid. About five of them meet with Amy once a month and they do things together. They go out for dinner, to movies, bowling and they had a holiday party. Amy has very long hair and even though her mother suggested that it might look nice if it were cut shorter, Amy decided that she wants to keep it long. Amy chooses her clothing and the food she eats. She makes her own lunch and shops for food with assistance, chooses the restaurants when she eats out and the movies she sees. She also attends

a day activity program at the local community college three days a week.

Amy is no longer waiting for supports since funding recently became available that makes it possible for Amy to be involved in community activities on a regular basis. Having one-on-one companionship is important for Amy because it makes her feel secure. One companion and Amy go out for dinner and to the movies; they go shopping and they attend a religious group for single people together. Amy has the opportunity to participate in activities like singing, attending cook-outs and baking cookies with the group. In addition, Amy stays with this companion at her house one weekend a month. There are two other young ladies who also are companions to Amy for a total of eight hours a week. They do things together that include going for long walks, shopping and going to the library. Even though her life is not easy, Amy now looks forward to having people come to spend time with her and the opportunity to regularly get out in the community to do the things she enjoys once again.

Real Lives, *continued*

Brian . . . Doing the Undoable

Brian is 28 years old. After he graduated from school in 1994, he worked at a sheltered workshop. He was not allowed to do much there because people saw his limitations and not his abilities. He wanted a job in the regular workforce but was told he had too many handicaps since he has low vision, cerebral palsy, scoliosis and he learns slowly. Brian and his family didn't give up. In January of 1999, a company hired Brian to form shipping boxes. Now he also shreds paper and stuffs envelopes there. Brian works ten hours a week and loves his job.

However, Brian wanted to do more and wanted to meet people. In January of 2000, he began to receive funding that enables him to have a support person with him two days a week. Tuesday mornings they go to the local hospital where they shred paper. Friday mornings they go to Brian's church and stuff bulletins. In the afternoons they pursue other interests. Brian has learned computer skills and can find radio stations on the Internet. This is his favorite activity when he is home. He also goes bowling, miniature golfing and visits video arcades. Brian is interested in different

places in the community and he has taken tours of fire stations, a newspaper company, a post office, a bank, and his local airport – including the air traffic control tower.

Brian likes to watch the planes and visit with the people he has met at the airport. He has been invited to board a lot of planes and learned that most executive jets have tiny kitchens, a small television for each passenger, lounge chairs and some even have a bedroom. Brian has met many nice pilots who have shown him the cockpits of the planes and told him a lot about flying. He has also ridden on the truck that fuels the planes and on the tug that pulls planes into the hangar. According to Brian, "I've made friends in my community, and I now have a job and two hobbies, airplanes and computers. I'm a very happy person."



Jeanette . . . We Are Never Too Old

Jeanette is 91 years old and retired. She lives in an apartment with a roommate and has an active life. She has been supported by the same provider agency for over 75 years but has been living without direct supervision for the past seven years.

Jeanette walks to the Downingtown Senior Center four days a week. While there, she works in the kitchen, prepares for parties, and plays cards and other games. When she learns a new card game that she particularly enjoys, she teaches it to other people she knows who do not attend the senior center. Jeanette also goes on senior center trips.

When Jeanette is not at the senior center, she does other things in the community. She is a member of a winter bowling league; she has many friends and uses paratransit to visit them; and she walks to her bank, a restaurant and a drugstore. One of her favorite hobbies is stenciling and she makes all of her own cards and stationery.

Staff provide support with her medical needs and take her grocery shopping. When they invite her to activities, Jeanette often declines the invitations saying that she is much too busy.

Carolyn: Self-Determination is for Everyone

Carolyn has lived in Philadelphia County all of her life. For 13 years she was receiving attendant care services through a provider agency. Now things have changed for her and she is in control. Carolyn said, "I told them who I wanted to be in my circle and what I wanted them to do." She told the people who support her what she wanted out of life and together they developed a plan. Carolyn's plan focused on making it possible for her to help people and to have her own apartment.

They put together a budget based on the cost of Carolyn's daily life and her support services. Then the plan and budget were submitted to the county for approval. For the first time, Carolyn's income was included in her budget. Because she was now in control of the decision, it was possible for her to pay her staff more. Instead of using a provider agency, Carolyn interviewed and hired the staff that would work for her. A payment agent, established by the county, keeps all of the personnel records on file to ensure compliance with federal, state, and local requirements.

Since the switch in control from the agency to Carolyn herself, things have not all been smooth but Carolyn now has the power to make decisions that affect her. She is able to go when and where she wants to go and do the things she needs to do. Carolyn believes, "It can work for everybody, even people who cannot talk, because their circle can help them take control of their lives. They know the person best and know how to support them in finding their own voice."

What Do People Want?

People and their family members want to have an everyday life that is typical of the general population. They want more in their lives and they have greater expectations of the system than they did ten years ago. People want to have self-determined lives. This means with the support of family and friends, they decide: how to live their lives; what supports they need; and how they want to spend the money in their individual budgets. It also means **they are responsible for their decisions and actions.**

Choice - in all aspects of life including the services they receive, who provides supports, where to live and with whom, where to work, recreation and leisure activities, vacations, planning individualized day activities, and having support provided at home.

Control - over their life including relationships, budgets and how money is spent, supports and services they receive, medical issues and planning.

Quality - of life determined by individuals. People want quality supports and services to enable them to have the life that they want. When they pay for high quality supports, they expect to get high quality.

Stability - feeling secure that all changes in their lives are made only with their input and permission – “nothing about me without me.”

Safety - to be safe at home, work, and school, in their neighborhood, as well as in all other aspects of their lives. People want services that ensure individual health and safety without being overprotective or restricting them.

Individuality - being known for their individuality and being called by their name. Being respected by having privacy of their mail, files, and history and being able to choose to be alone at times.

Relationships - with family, partners, neighbors, community people such as pharmacists, barbers and grocers, support staff and having friends they choose.

Freedom - to have the life they want and to negotiate risk. People want freedom from labels and other people to use “People First” language. Individuals have the same rights afforded to all citizens. They want to exercise the freedoms of choice, to associate with people they choose, to move from place to place, and to use complaint and appeal processes.

Success - freedom from poverty and having a chance to be successful in the life they choose. Living independently with sufficient support to be successful and having expanded opportunities for employment with supports provided as needed.

Contributing to the Community - being full citizens of the community, voting, working for pay or volunteering, participating in leisure and recreation activities, belonging to a religious community, owning or renting one's own home, living among family and friends and not being segregated. People want to be recognized for their abilities and gifts and to have dignity and status.

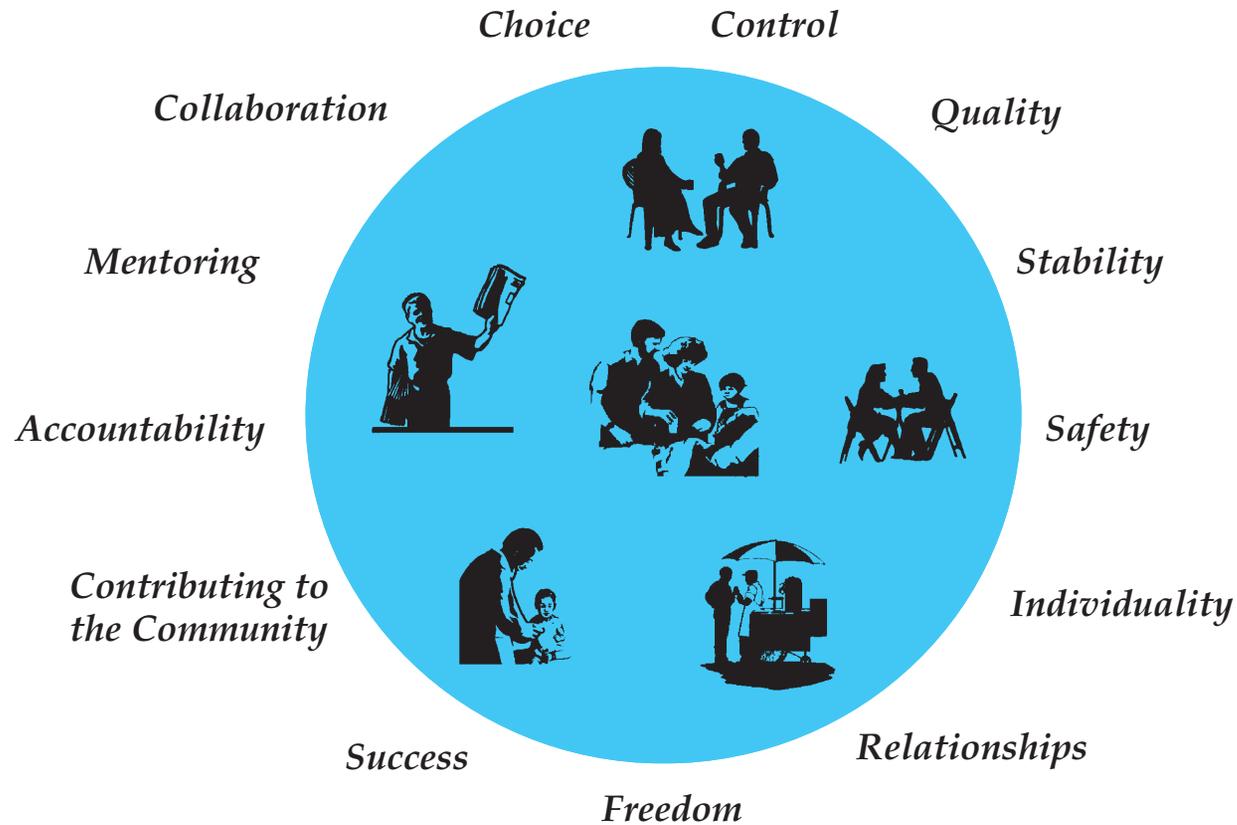
Accountability - government (state and county), agencies, and support people will do what they are supposed to do. This includes providing supports that people need when they need them and making sure that they don't lose supports that they already have.

Mentoring - individuals and families trained as mentors to help other people and families by providing information and working with them until they can do things on their own; experienced supports coordinators mentoring new supports coordinators; senior support staff mentoring new support staff; and individuals and families mentoring support staff.

Collaboration - between the Office of Mental Retardation and other Offices within the Department of Public Welfare and between the Department of Public Welfare and other state Departments. People want collaborative planning during times of transition. They also want a seamless system that bridges from education to adult services. In addition, people want to have just one plan to be shared by all people/services/systems that are involved with them.



People Want Everyday Lives



Individuals and their families have the passion to make everyday lives a reality.

Beliefs

In order to change the system to make Everyday Lives a reality for everyone, then we all must keep in mind the following beliefs:

- Self-determination is for **everyone**.
- Everyone can make choices.
- Everyone should have control over his or her life.
- Everyone is different and there is value in difference; therefore supports need to be individualized.
- Everyday Lives are for **everyone**.



Remaining Challenges

Even though more people are beginning to have everyday lives, many challenges remain.

- Self-determination needs to be a way of life.
- Communication on all levels of the service system needs to be improved. Individuals need to have low and high technology devices available to assist them in communicating with other people.
- Transportation needs to be accessible, affordable, and available where and when people need it.
- The waiting list for supports and services needs to be eliminated.
- Capacity needs to be expanded to accommodate more people and meet more complicated needs.
- Local systems and individuals and their families need to work together.
- Quality needs to be continually improved.
- All people with disabilities need to be accepted as valuable members of the community.

Framework for the Future

Our vision for the future is a time when everyone has an everyday life. There is still much work that needs to be done before this will become a reality for all people. The system needs to move to an individual basis from a collective program model. Self-determination needs to be a way of life for everyone. Pilot projects make people think that it is only for a limited number of people but everyone can make choices and have control over their lives.

Everyday Lives and *Self-Determination* need to be the basis for everything.

Communication

- Individuals and families need to have more information and be informed in language they can understand.
- Individuals and families need to receive information in a timely fashion.
- Communication needs to continue in forms other than technology, for example, paper format and by telephone where an individual or family member can call and talk with a person who can explain things.

- Supports coordinators need to *meet* with all individuals/families to complete forms that are used in the evaluation of need of services.
- Individuals need to have low and high technology devices available to assist them in communicating with other people.
- There is a need to listen to what people are saying through their words and actions.
- There is a need to listen to what families and support people are saying.
- Computers should be used to eliminate the need for individuals, families, and agencies to repeat the same information.
- People need access to a great deal of information without jeopardizing confidentiality.

Framework for the Future, *continued*

Individualized Planning and Supports

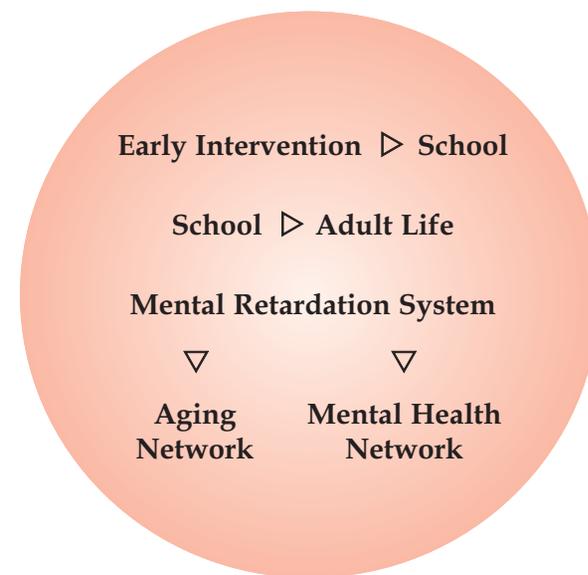
- Everyone should have the opportunity to have an individual plan that can be either informal or formal and a budget they create with help from people they choose. The plan can be as simple as a list or formal such as a Person-Centered Plan, Essential Lifestyle Plan or a MAP. The plan needs to be valued and followed by everyone providing supports. It should be used as a tool to promote action and it should dictate staffing needs for the person. Some people will choose not to do formal planning and they should receive the necessary support to help them identify and list some short-term needs.
- Supports must be there for individuals and families too.
- Families need “future planning for families” education.
- People need information about providers of supports and services so they can make good choices.
- Individuals and family members want to have their own lives. Supports are needed all week long, including weekends and in the evening. There needs to be an emphasis on building relationships with friends, family members, neighbors, and other people in the community.
- Real jobs with good wages and benefits need to be promoted.
- Transportation needs to be available where and when people need it, at a reasonable cost.
- Community employers need to value workers with disabilities and make accommodations to people’s needs.

Control

- People need the opportunity to make choices in all aspects of their lives.
- More choices need to be provided in living, working and having fun.
- People need to have more opportunities to make decisions.
- People need to be in control of choosing agencies and individuals to provide supports, hiring and firing staff and choosing supports coordinators.
- People and their families need to be involved in all decisions about their lives.
- Individuals and families need to be respected and have input into the system. They need to be equal participants in all levels of decision making, such as serving on governing boards.
- Local mental retardation systems need to build relationships with individuals and families. They need to provide enough information to individuals and families to empower them so they can gain control of their lives.

System Issues

- The system needs to have adequate capacity and funding so the waiting list is eliminated.
- Outreach needs to be done to find individuals unknown to the system and information on their needs must be collected before a crisis occurs.
- Local systems need to work together with individuals and families and respect them.
- Efforts need to continue in recruitment and retention of direct care staff.
- Quality of life and supports need to be evaluated from an individual's and family point of view.
- The system needs to be visionary. (Imagination and creativity must be encouraged to develop unique support options that meet individual needs.)
- Supports coordinators need to be limited to 35 or less people they support so they can provide a quality service.
- Support people need to have appropriate training and to be better informed.
- People who provide supports and services need to be paid a living wage.
- The system needs to recognize that all jobs, full time, permanent part-time and volunteer jobs are real jobs and not a social service. Supports coordinators should not visit people at their jobs or take them away from work.
- The public needs to be educated concerning the value of people with disabilities in the community.
- Mentoring needs to be expanded so it includes experienced supports coordinators to new supports coordinators; senior support staff to new support staff; and individuals and families to support staff. Supports coordinators who are mentors need to be relieved of other duties.
- People should not be identified in such a way that it sets them apart from others in the community and draws undue attention to them.
- Agencies need to be educated on providing consumer/family directed supports and services.
- Counties and agencies need assistance in making the transition to consumer directed services.
- The system needs to provide access to appropriate health care for people and assure their safety.
- Better inter-systems communication is needed. Early intervention to school; school to adult life; mental retardation system and aging network and mental health network.



Framework for the Future, *continued*

When the remaining challenges are finally addressed, this is the story we will tell:

All children go to school with neighborhood children and spend leisure time with them as well. People who provide supports and services are paid a living wage and are chosen by the individual and their family. Supports coordinators work with few enough individuals that they periodically call to ask, "Is there anything I can do for you?" and they develop a relationship with the person and his or her family and friends. They listen to individuals and families and they see the capabilities of individuals. Supports coordinators work flexible hours so they can meet with individuals and families when it is convenient for individuals and families.

Planning for the transition from school to work or school to higher education begins in the early teen years. Students and their families learn about possible options for after graduation and students get real life experience in a variety of settings while still in the school program. There is a seamless transition from school to adult life and people have the support they need to be successful at a job or in continuing their

education. Those who traditionally could not get jobs, are given the opportunity to do "job sharing" where each person sharing the job, does the part he or she is able to do with necessary support being provided.

Young adults decide who will help them with planning. Together they create a plan focused on the life they want, what kinds of supports they need, how much they cost, and how they will spend their individual budget. Individuals, along with family and friends they choose, have control.

People have friends of their own, not their parents' friends, with whom they go out for lunch and socialize. They go on dates and some will marry. Transportation is available and affordable to get people where they want and need to go, when they want. It is available on weekends and evenings so they can have a social life.

When they become adults and decide they want to move from the family home, the people who provide support work together with the individuals to make it happen. People receive assistance in learning about housing options and how to have a home of their own.

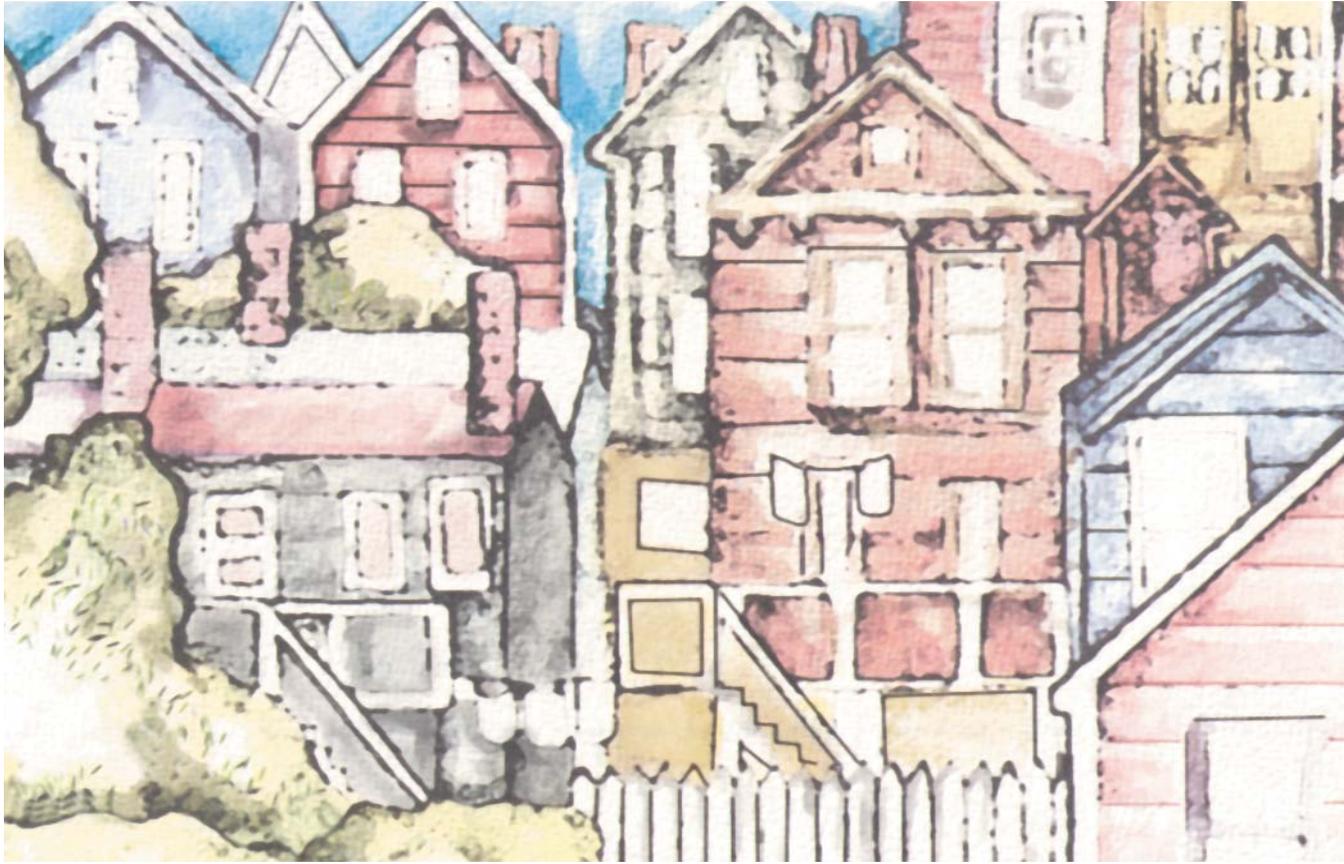
As people age and would like to retire there is another transition. Perhaps they work just a few days a week or shorter hours each day and they are given the opportunity to explore what the community has to offer for retirement on their days off. They have the support they need so they can plan how to spend their days and evenings doing what they enjoy.

Paid support people work flexible schedules so individuals have an everyday life, every day of the week including evenings.

After comparing what life was like ten years ago and what it is like now, we can say that we have made progress. Everyday lives are beginning to happen for people in Pennsylvania.

**Making Everyday Lives happen
for *all people* is our goal!**





Planning Advisory Committee Members

November 2001

Advisory Committee for MH/MR

Rocco Cambria

Autism Support & Advocacy in PA

Virginia Leonard

Developmental Disabilities Council

Graham Mulholland
David W. Golin

Early Intervention Providers Association

Michele Myers-Cepika
Pat Eberley

MH/MR Program Administrators Association of Pennsylvania, Inc.

Michael D. Chambers
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Ellie Myers
Mary Beth Mahoney
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Pennsylvania Association of Rehabilitation Facilities

Gene Bianco
Nathaniel J. Williams
Ronald E. Rucker

Pennsylvania Association of Resources for People with Mental Retardation

Shirley Walker
Dennis Felty
Russell Rice

Pennsylvania Community Providers Association

George Kimes
Dennis Oswald
Peggy Van Schaick

Pennsylvania League of Concerned Families of Retarded Citizens, Inc.

Polly Spare
Bertin W. Springstead

Pennsylvania Protection & Advocacy

Kevin Casey
Maureen A. Devaney
Liz Healey

Pennsylvania Waiting List Campaign

Nancy Murray
Bonnie Miller
Sheila Stasko

Prader-Willi Syndrome Association of PA

Doris Jane Miller

Self-Advocates

Carolyn Morgan
Oscar Vargas
Michael Rhine
Wanda Davis
Donald Angermier
Mike Smith
Oscar Drummond
Karin Knorr

State Intragency Coordinating Council

Kathy Brill

The Arc - Pennsylvania

Janet Albert-Herman
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Martin Murray
William Burke
Gay P. Vroble
Linda Drummond

United Cerebral Palsy of Pennsylvania

Joan W. Martin
Susan Tachau

Temple University Institute on Disabilities/ University Center for Excellence

Diane N. Bryen



Health Promotion Activities Plan

Name of Individual:

Health Concern/Issue * (Diagnosis)	
Related Body System	Vision Respiratory Lymphatic Dental Hearing Digestive Integumentary (Skin) Endocrine Cardiovascular Nervous Musculoskeletal Genitourinary Blood
What is it? (Provide definition)	
Signs and Symptoms (general)	
Signs and Symptoms (specific to the person):	
Promotion/strategy support required * List very specific steps that the individual and/or caregivers use to support the person's health condition. Include information about monitoring health status. Who is called for changes/ problems in this person's health condition? What is tracked, where it can be found, and who follows up on documentation required for this health condition? Who provides what training for the person and staff about the health condition and when?	
Frequency of support *	
Desired outcome *	
Person/agency responsible *	

* FIELDS FOUND IN THE HEALTH PROMOTION SECTION OF THE ISP

Health Promotion Activities Plan

****This sample is to assist you in developing a health promotion activity plan. It is not intended to replace medical advice. Any instructions given by the physician regarding this diagnosis must be included.**

Name of Individual:

Health Concern/Issue * (Diagnosis)	SEIZURE DISORDER
Related Body System	Vision Respiratory Lymphatic Dental Hearing Digestive Integumentary (Skin) Endocrine Cardiovascular Nervous Musculoskeletal Genitourinary Blood
What is it? (Provide definition)	Episodes of abnormal electrical discharges in the brain that causes abnormal motor or sensory activity.
Signs and Symptoms (general)	There are many different types of seizure activity. Generalized seizures have the following signs/symptoms: loss of consciousness, body stiffens; rhythmic jerking of arms and legs, possible incontinence of urine/feces, individual is usually tired after it is over.
Signs and Symptoms (specific to the person)	
Promotion/strategy support required * List very specific steps that the individual and/or caregivers use to support the person's health condition. Include information about monitoring health status. Who is called for changes/ problems in this person's health condition? What is tracked, where it can be found, and who follows up on documentation required for this health condition? Who provides what training for the person and staff about the health condition and when?	<ul style="list-style-type: none"> ➤ Watch <u>(name of person)</u> for signs and symptoms listed above and report immediately to <u>(title of person in agency who is responsible to receive this information)</u>. ➤ Give medication as ordered (see Medication Administration Record/Log). If a prn (as needed) medication is given, the result must be documented per agency policy. ➤ <u>Include any specific instructions from the treating physician.</u> ➤ Observe safety precautions at all times (never leave unattended during bathing or swimming). ➤ Call "911" if a seizure lasts longer than 5 minutes, if the person seems to have any breathing difficulty, or if the person suffers an injury during the seizure that requires emergency intervention. ➤ Antiepileptic medication levels will be checked at the frequency determined by the physician but at least every six months. Copies of these laboratory tests will be filed in the Medical Record under <u>(list section here)</u>. ➤ Documentation about this condition can be found in the medical record under <u>(list section here)</u>. ➤ Receive training regarding this diagnosis and plan of care (include when to notify the physician) by <u>(title of person who provides medical training)</u> at least <u>(indicate frequency of training)</u> or as changes occur. This should be documented for all staff in the home.
Frequency of support *	<u>Fill in what physician (e.g. primary care physician, neurologist) treats this condition and how often the person is seen.</u>
Desired outcome *	<u>(Name of person) will be seizure free or not suffer injury during a seizure.</u>
Person/agency responsible *	<u>(Name of person), caregivers, agency nurse, primary care physician, (specialist, if applicable)</u> <small>(The responsible parties may vary according to your agency; please place specific roles in this section. Some other examples might be health care coordinator, program specialist, house manager.)</small>

* FIELDS FOUND IN THE HEALTH PROMOTION SECTION OF THE ISP

POLICY ON PERSON-CENTERED SUPPORTS FOR PENNHURST CLASS MEMBERS WHO ARE HOSPITALIZED

**Issued by the Pennhurst Management Team
December 1, 1997**

The Pennhurst Management Team is issuing this policy to provide direction for community residential provider agencies and their staff in the provision of needed supports to Pennhurst class members who are hospitalized for physical health problems. This policy addresses agency responsibilities during and after the hospitalization. *This policy requires that members of the Pennhurst class be provided with necessary and required awake staff support during inpatient hospitalization for physical health reasons. The determination of what constitutes necessary and required staff support will be made by the team as soon as it is known that the individual will be, or has been, admitted to the hospital.*

INTRODUCTION

People with mental retardation are presented with particular challenges when they are hospitalized either on an emergency basis or for planned procedures. Some of the challenges that are presented include:

- People who are unable to communicate in traditional ways often have difficulty in clearly expressing their needs to hospital staff. Due to these difficulties with communication, hospital staff may be unsuccessful at providing explanations of and reasons for procedures.
- For people with difficulties in perception, comprehension and expression, the unfamiliar routine of the hospital and its staff and the anticipation of unknown medical procedures can create a state of heightened anxiety and stress.
- Due to the generally limited availability of nursing personnel in many hospitals, and the lack of training provided to hospital staff regarding individuals with mental retardation, these individuals historically have been underserved in hospital settings.

RESIDENTIAL AGENCY SUPPORT STAFF RESPONSIBILITIES

General Responsibilities

The primary responsibility of residential agency staff is to support to the individual. Residential agency staff are not expected to replace hospital staff or assume hospital staff functions. The manner in which residential agency staff provide supports is contingent upon the specific hospital policies which apply. For example, if the individual is in intensive care, staff may be permitted in the individual's room only during certain hours.

Residential agency staff responsibilities include assisting the individual to eat and perform personal hygiene tasks and making the individual as comfortable as possible in the hospital setting. Staff should check with hospital personnel prior to providing

assistance to the individual to ensure that all necessary precautions are taken. No tasks should be undertaken that may be contraindicated by the individual's physical condition as determined by the individual's physician, by the hospital's policies, or by the individual's wishes.

Residential agency staff should provide emotional support and companionship to the individual during the hospitalization. Staff should support the individual in expressing his wishes, preferences and desires regarding day to day care and comfort.

Residential agency staff should assist the individual in participating in examinations and medical procedures unless the individual declines assistance. Staff should consult with individuals, whenever possible, to determine whether or not they wish to have staff remain with them in the hospital room during visits from medical personnel.

Residential agency staff are expected to maintain a communication log in the individual's hospital room, as described below. In addition, they should act as a communication liaison between the individual and hospital staff to support the individual in understanding what is transpiring within the hospital setting and to assist the individual in communicating his needs.

Residential agency staff are expected to advocate for the preservation of the individual's rights such as the right to privacy and confidentiality. They are not permitted to sign consent or permission forms for the individual unless in keeping with applicable Commonwealth regulations.

Finally, residential agency staff should be considerate of the needs of other patients and consult with the hospital staff should any potential or actual conflict arise with other patients and their visitors.

Communication Log

Residential agency staff are expected to maintain a communication log in the individual's hospital room. This log should be used to document the staffs' observation of the individual and his status and any information they receive during the hospital stay. The log should include any observations and information regarding the following:

- a. the type and amount of food and liquid consumed;
- b. indications of discomfort;
- c. indications of pain;
- d. duration, frequency, and nature of sleep;
- e. skin breakdown;
- f. frequency of elimination;
- g. type, duration and time of activities which occur;

POLICY ON PERSON-CENTERED SUPPORTS FOR PENNHURST CLASS MEMBERS WHO ARE HOSPITALIZED

*Issued by the Pennhurst Management Team
December 1, 1997*

- h. the provision of any treatments and therapies;
- i. any medical consults which occur;
- j. any physician visits;
- k. any other relevant observations or incidents; and,
- l. the individual's level of responsiveness.

The communication log should be routinely updated and each entry should be signed.

The log should include a list of telephone or beeper numbers for the health care decision maker, if any, the designated health care support person, other agency staff, including the agency nurse, supervisory staff and the individual serving as the single point of contact, and family members and close friends. A staffing schedule should be kept with the log. The appropriate residential supervisory staff should be notified if a staff member does not report for work as scheduled.

Communication Liaison Expectations

Residential agency staff should communicate with hospital personnel as needed to ensure an individual's needs are addressed. In addition, they should communicate with the individual serving as the single point of contact regarding their observations and any information necessary to ensure the person's well-being in the hospital.

Relationship to Hospital Personnel

Residential agency staff are expected to work cooperatively with hospital personnel. They are never to assume the role of hospital personnel. However, they may assist hospital personnel in accomplishing a task in limited circumstances consistent with the responsibilities listed above.

Residential agency staff should communicate to hospital personnel any information documented in the communication log, such as, how the individual is eating or drinking, indications of discomfort, pain, and skin break down. Regular access to the log by hospital personnel should be encouraged.

Residential agency staff should notify hospital nursing staff if they need to leave the individual's room for any reason.

SINGLE POINT OF CONTACT

The residential provider agency should appoint an individual to serve as the single point of contact for communication related to the individual's hospitalization. While in most case this individual will be the designated health care support person, in some circumstances another individual may assume this role. This individual is responsible for

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facilitating communication between the attending physician and team members including the designated health care support person, health care decision maker, the family, the case manager, and agency staff.

This individual should contact the hospital social worker as soon as possible after the hospital admission to establish their communication protocol. The appropriate hospital personnel should be given the necessary information to contact this individual on a 24 hour basis.

This individual is responsible for contacting the Special Needs Unit of the individual's HMO to notify them of the individual's hospitalization and relay relevant information.

This individual should ensure that the hospital has copies of the individual's current medical history summary, current chronic health problems list, current medications list, current physician names and phone numbers as well as any other relevant information about the person, such as allergies and likes and dislikes.

It is especially important that the individual designated to provide medical consent is regularly and accurately apprised of the individual's status during the hospital stay. This individual is expected to maintain regular contact with the agency staff supporting the individual during his stay at the hospital. This individual is responsible for communicating pertinent health care information to relevant agency staff, team members, the individual's family, case managers, and others on a need to know basis.

RESIDENTIAL AGENCY NURSE RESPONSIBILITIES

As a member of the individual's team, the agency nurse provides clinical expertise, clarifies medical information, identifies staff training needs and intervenes on behalf of the individual when medical necessity dictates. The agency nurse also serves as the communicator regarding complex medical needs to agency staff, county staff, the health care decision maker, designated health care support person, and community medical personnel.

The agency nurse may serve as the single point of contact. If the agency nurse does not serve as the single point of contact, he should maintain close contact with agency staff supporting the individual during his stay at the hospital. The agency nurse is expected to provide oversight of the health status of the individual and of the quality of supports which are needed during the hospitalization.

The agency nurse should provide clinical support in the development and implementation of discharge plans. This includes assessment of the readiness of the

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*Issued by the Pennhurst Management Team
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individual for discharge, requirements for additional equipment or outside staffing support, and agency staff training to facilitate the transition back to the individual's home. The agency nurse should work with the team to identify, create and maintain documentation necessary to monitor the individual's health once he returns from the hospital.

The agency nurse should serve as the liaison with providers of home health care supports, including nursing services, durable medical equipment, and specialized therapies, to ensure that adequate services are being provided and to coordinate those services with residential agency staff.

HEALTH CARE DECISION MAKING

Authority for making health care decisions should be established prior to a planned hospitalization or as soon as possible in an emergency hospitalization. Options for health care decision maker include the person (if he is able), a family member, a guardian or the provider (per the Commonwealth of Pennsylvania Office of Mental Retardation Bulletin # 00-90-02, *Substitute Decision Making Medical Treatment*, January 17, 1990).

The team, including the designated health care support person, the agency nurse, agency staff supporting the person in the hospital and the individual serving as the single point of contact should all be aware of who the health care decision maker is and how to contact that person. During a hospitalization the attending physician and other hospital personnel should be made aware of the identity and the scope of authority of the decision maker.

The health care decision maker should be notified as soon as possible when an individual is hospitalized on an emergency basis. He must be included in discharge decision making and planning.

DISCHARGE PLANNING

As soon as possible after the person is admitted to the hospital, the hospital social worker should be asked to contact the hospital discharge planner on behalf of the individual. The individual serving as the single point of contact should ensure that any needed staffing, medical equipment, treatment, or emotional supports and accommodations will be available to support the individual upon discharge to his home or alternative treatment facility.

The Special Needs Unit staff of the individual's HMO must be notified, by the individual serving as the single point of contact, of the projected discharge date and must be

POLICY ON PERSON-CENTERED SUPPORTS FOR PENNHURST CLASS MEMBERS WHO ARE HOSPITALIZED

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included in discharge planning. The Special Needs Unit should be informed of any relationships the residential agency has with a home health services provider, pharmacy, or durable medical equipment provider to facilitate the use of those providers if they are members of the HMO's provider network.

When planning for discharge the team should consider the following:

- * can the individual resume his normal activities?
- * will the individual require any new or additional health care services or equipment?
- * do agency staff need additional or specialized training or resources to support the individual?
- * does the agency agree with the decision to discharge? If not, what steps can the agency take to address the situation?

ASSISTANCE WITH IMPLEMENTATION

Questions regarding this policy should be directed to the Pennhurst Management Team's Director of Health Services or to the Quality Assurance Program Analysts. Requests for technical assistance to support implementation of this policy should be directed to Philadelphia Coordinated Health Care.

hospolicy.doc

POLICY ON PERSON-CENTERED SUPPORTS FOR PENNHURST CLASS MEMBERS WHO ARE HOSPITALIZED

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December 1, 1997*

Nursing Assessment

Individual: _____ Date: _____ Time: _____

Vital Signs:

Pulse: _____ Respirations: _____ Blood Pressure: _____ Temperature: _____

Neurological Status:

Level of Consciousness: Alert Oriented
 Confused Slow to respond/comprehend History of seizures Seizure precautions
 Disoriented Lethargic Vertigo Other
Pupils: R _____ L _____
Sensory Limitations: None Noted Prescribed Used
 Taste Speech Sight Glasses _____
 Touch Smell Hearing Hearing Aid _____

Comments:

(describe abnormal findings)

Functional Status (Level of Self Care):

Mobility: No limitations Devices to aid mobility:
Limitations: Walking None
 Transfer Cane, crutches, walker
 Turning in bed Artificial limbs R _____ L _____
 Stairs Brace
 Standing
 Generalized weakness
 Other
Weakness/paralysis:
 Upper extremity R _____ L _____ Lower extremity R _____ L _____
Assistance required:
 Hygiene/Grooming
 Dressing
 Meals
 Other

Criteria for fall prevention:

Age 65 or older
 Altered mental status
 History of falls
 Impaired mobility/balance
 Ambulatory device
(cane, walker, wheelchair)
 Any of the following meds:
sedatives
narcotics
diuretics
muscle relaxants
antihypertensives

Individuals who meet two or more criteria are at risk.

Respiratory:

Accessory muscles Normal limits (rate) Nasal flaring
 Dyspnea Secretions Tracheostomy
 Orthopnea Abnormal breath sounds Seasonal breathing difficulties
 Cough Oxygen Other

Oxygen rate and delivery method:

Pulse Oximetry reading: _____

Cardiovascular:

Regular rhythm, rate within normal limits
 Abnormal pulses Abnormal heart sounds Pacemaker
apical/radial/pedal Jugular vein distension Calf tenderness
 Edema Other
 Vascular access device (type): _____

Elimination:

Bladder: Voids clear, yellow urine Bowel: Bowel sounds (active, hypo, hyper)
 Nocturia Other Abdomen soft, non-tender
 Burning Catheter Last BM: _____
 Urgency Date Placed _____
 Urinary incontinence
 Urinary frequency
 Stress incontinence Intake Total: _____ Output Total: _____

<p>Skin:</p> <p><input type="checkbox"/> Normal turgor, temperature & color <input type="checkbox"/> Intact mucous membranes</p> <p><input type="checkbox"/> Edema <input type="checkbox"/> Cyanotic <input type="checkbox"/> Dry <input type="checkbox"/> Flushed <input type="checkbox"/> Diaphoretic <input type="checkbox"/> Pale <input type="checkbox"/> Jaundiced <input type="checkbox"/> Rash <input type="checkbox"/> Scaly <input type="checkbox"/> Other</p> <p>Skin Assessment Code</p> <p>A Abrasions Br Bruises Bu Burn L Laceration P Pressure Ulcer Grade I, II, III, IV (circle) R Rash S Scar</p> <p>Devices to aid skin protection <input type="checkbox"/> None <input type="checkbox"/> Protective boots <input type="checkbox"/> Other _____</p>	<p>Potential for skin breakdown:</p> <p><input type="checkbox"/> Poor general health <input type="checkbox"/> Decreased mental status <input type="checkbox"/> Decreased oral/fluid intake <input type="checkbox"/> Incontinence <input type="checkbox"/> Decreased activity <input type="checkbox"/> Immobility <input type="checkbox"/> No problems</p> <p>Individuals who meet four or more criteria are at risk for breakdown.</p>
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<p>Psychosocial:</p> <p><input type="checkbox"/> Appearance, behavior, verbalization appropriate to situation <input type="checkbox"/> Concerns expressed by individual/caregiver <input type="checkbox"/> Other</p>	
---	--

<p>Nutrition:</p> <p>Current weight: _____ as of _____ (date)</p> <p><input type="checkbox"/> Increase or decrease in weight (circle) Amount: _____ Time period: _____</p> <p><input type="checkbox"/> Dietary restrictions <input type="checkbox"/> Dentures <input type="checkbox"/> Swallowing difficulty <input type="checkbox"/> Other concerns: _____</p>	
---	--

<p>Pain: <input type="checkbox"/> No reports or indication of pain noted</p> <p><input type="checkbox"/> Location <input type="checkbox"/> Severity <input type="checkbox"/> Pain relief methods used (list): _____</p>	
--	--

<p>Adaptive Equipment:</p> <p><input type="checkbox"/> Working order <input type="checkbox"/> Repairs needed (list): _____</p>	
--	--

<p>Wound/Incision/Stoma Care:</p> <p>Location (identify site): _____</p> <p>Sutures/clips: _____</p> <p>Drains (type): _____</p> <p>Drainage (type): _____</p> <p>Time Dressing Changed: _____</p>	
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<p>Other:</p> <p>_____</p> <p>_____</p> <p>_____</p>

Signature of Nurse: _____

SPECIAL SERVICES FUND
FOR
PENNHURST CLASS MEMBERS

The City of Philadelphia Department of Public Health has established a Special Services Fund, designed to pay for reasonable costs of necessary medical and dental care that are not covered by Medical Assistance, Medical Assistance HMOs, Medicare, or other insurance.

This fund has been created to ensure that Pennhurst class members have appropriate access to necessary health care and dental services. The fund will not cover services that can be paid for through existing health care or dental coverage and is not intended to cover recurring costs. Philadelphia Coordinated Health Care (PCHC) has responsibility for administering this fund with the City's direction and oversight.

The following guidelines have been established so that funding may be provided as efficiently as possible. Please read these guidelines carefully and complete the attached application form to begin the process to access the fund.

- 1) All requests for funding assistance must be received and approved by PCHC at least six weeks PRIOR to the delivery of services. This time frame is necessary for PCHC to process the request and to ensure timely payment to the health or dental care providers. PCHC will not process requests for funds either after the service has been rendered or in a shorter time frame unless an emergency situation exists.
- 2) All requests for services MUST document that payment for the service(s) described will NOT be provided by Medical Assistance, a Medical Assistance HMO, Medicare, private insurance, or provider agency funds.
- 3) As deemed appropriate in the Office of Mental Health/Mental Retardation Client Funds Policy {sequential number GEN-16-89, section number 6.12.18, page 62}, individuals and/or provider agencies are asked to contribute toward the "...purchase of medical or dental services to the extent that such funds are available".
- 4) Individuals who are members of a Medical Assistance HMO and require sedation or anesthesia for dental care, should request this service through the HMO. PCHC is available to assist in this process.
- 5) PCHC reserves the right to request second opinions for health related services and may request that an alternative health practitioner be used.

If your situation meets all of the above criteria, and you wish to apply for funding assistance, please complete the attached application and return it to PCHC at the address provided on the application.

**Philadelphia Coordinated Health Care
Special Services Fund Application**

Please complete and return to the attention of the Health Care Community Outreach Specialist:

1601 Market Street, 5th Floor, Philadelphia, PA 19103 (215) 546-0300 or FAX: 215-790-4976

Name of Person Completing Form:		Telephone #:
Name of Individual:		Date of Birth:
Address:		Social Security #:
Agency Name:		Agency Phone #
Agency Contact:		County Case Manager Name:
Member of Plaintiff Class? <input type="checkbox"/> Yes <input type="checkbox"/> No If Yes, <input type="checkbox"/> Pennhurst <input type="checkbox"/> Dual (Penn/Emb)		
Type of Residence: <input type="checkbox"/> CLA <input type="checkbox"/> ICF/MR <input type="checkbox"/> Life Sharing <input type="checkbox"/> Own Home <input type="checkbox"/> Boarding Home <input type="checkbox"/> Domiciliary Care <input type="checkbox"/> Semi-independent <input type="checkbox"/> Independent <input type="checkbox"/> PLF <input type="checkbox"/> Other: _____		
Medicare Part D/Prescription Drug Plan - Name/ID Number _____		
Medical Assistance, HMO Type: <input type="checkbox"/> AmeriChoice <input type="checkbox"/> Keystone-Mercy <input type="checkbox"/> HealthPartners		
Medical Assistance (ACCESS) #:		
Medicare? <input type="checkbox"/> No <input type="checkbox"/> Yes If "Yes", Membership #: _____ <input type="checkbox"/> Part A? <input type="checkbox"/> Part B?		
Private Health Insurance? <input type="checkbox"/> No <input type="checkbox"/> Yes If "Yes", Insurance Company Name: Policy Number:		
Primary Care Physician Name:	PCP Phone:	
Primary Care Dentist Name:	PCD Phone:	
Reason for last dental visit:	Date of last dental visit:	
DESCRIBE SERVICES REQUESTED:		
<p>Is treatment statement (description of service(s) from PCP attached? <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>Has written supporting documentation been attached from medical insurer verifying decline of coverage for service(s) requested? <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>Is the individual or agency able to contribute funds toward payment of the requested service(s)? <input type="checkbox"/>No <input type="checkbox"/>Yes If "Yes", provide amount here: \$</p>		
COMMENTS: (use reverse side if additional information is needed)		
To the best of my knowledge, all information contained in this form is accurate:	Print Name & Signature:	
FOR USE BY PCHC:		
Date Processed:	PCHC Staff Responsible for Follow-up:	
Supervisory Approval:	Approval for Disbursement (Director):	
Type of Action Taken:		

GLOSSARY

Abatement – a complete or partial cancellation by the County Administrator of a consumer’s financial liability for treatment or services.

Abuse – of an adult individual with a developmental disability includes, but is not limited to:

- any death caused by other than accidental or natural means or occurring in unusual circumstances;
- any physical injury caused by other than accidental means or that appears to be at variance with the explanation given of the injury;
- willful infliction of physical pain or injury;
- sexual harassment or exploitation;
- failure to act or neglect that leads to or is in imminent danger of causing physical injury, through negligent omission, treatment or maltreatment of an adult;
- verbal mistreatment;
- placing restrictions on an individual’s freedom of movement by seclusion or restricted access unless agreed upon with the individual support plan team and documented within the Individual Support Plan (ISP);
- using restraints without a written physician’s order unless the individual’s actions pose imminent danger to self or others or is approved in the individual’s ISP;
- financial exploitation.

Access Card – Department of Public Welfare issued card that is pre-programmed for eligible services.

Activities of Daily Living – Daily life tasks that include dressing, nutrition, homemaking, personal hygiene, communication, travel, and safety in the home.

Adaptive Behavior Scale – An assessment of an individual’s level of skills. There is a score at the end that indicates strengths and deficits.

Adult Day Service (ADS)/Adult Development Training (ADT) – program which helps individuals with severe and/or multiple disabilities develop and improve personal and vocational skills. Instructional areas may include communication, socialization, cognitive education, motor development, daily living skills, community education and recreation.

Adult Training Facility – A place where day supports are provided to adults who need help in developing skills, meeting personal needs and completing basic daily activities to persons with intellectual/developmental disabilities age 18 or younger.

Advance Directive – A document signed by an individual indicating his/her preferences for medical treatment.

Advocate – A person who assists an individual in expressing and achieving his/her desires and needs.

Agency – term used when identifying or referring to the non-profit or for profit organization that provides residential and/or employment services to a person with intellectual/developmental disabilities.

Alternative to employment – includes services for individuals whose age or condition preclude employment situations. The overall purpose is to provide opportunities for integration, independence and productivity, which are based on the individual's needs.

Americans with Disabilities Act (ADA) – The ADA is a federal statute that guarantees rights and access to people with disabilities. It prohibits discrimination on the basis of disability in employment, programs and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities. The ADA was signed into law on July 26, 1990. It contains requirements for new construction, for alterations or renovations to buildings and facilities, and for improving access to existing facilities of government that provide programs offered to the public. The ADA also requires effective communication for people with disabilities, establishes eligibility criteria that may restrict or prevent access, and requires reasonable modifications of policies and practices that may be discriminatory.

Applied Behavioral Analysis – A data-driven analysis of behavior and teaching strategies to establish a baseline of skills and specify an appropriate curriculum.

Base Service Unit (BSU) – The agency responsible for assessment and intake of individuals into the county system. It provides supports coordinator services.

Case Manager (Supports Coordinator) – an employee of the community mental health program or other agency that contracts with the County Mental Health and Developmental Disability Program or with the state Mental Health and Developmental Disability Services Division, to plan, procure, coordinate, monitor individual support plan (ISP) services and to act as an advocate for the individual.

Center for Medicare and Medicaid Services (CMS) [formerly known as HCFA] – The federal agency in the Department of Health and Human Services (HHS) that administers the Federal Medicaid Programs including the Medicaid Waiver.

Community Health Review – a tool utilized by HCQU nurses to evaluate and assess the physical, behavioral and mental healthcare needs of persons with intellectual/developmental disabilities in the community when other resources have been exhausted.

Community Home/Community Living Arrangement (CH/CLA) – community-based residential programs, which provide care and support services to one or more individuals in a home setting.

Delegation – means that the Registered Nurse (RN), or Licensed Practical Nurse (LPN), at the discretion of the Registered Nurse, authorizes an unlicensed person to perform a basic task of client care with knowledge that the unlicensed person has been taught the task, and is competent to perform the task. Delegation may require, at the discretion of the RN, that a licensed nurse periodically supervise and evaluate the unlicensed person performing the basic task of client care.

Department of Public Welfare (DPW) – a department of the state government which administers human service programs distributes federal and state funds to local agencies and develops programs to respond to the human service needs of the Commonwealth's residents.

Developmental Disability (DD) – a disability attributable to mental retardation, autism, cerebral palsy, epilepsy or other neurological condition that affects an individual's ability to function independently, and the disability:

- originates before the person attains the age of 22 years, except that in the case of mental retardation the condition must be manifested before 18 years of age; and
- has continued, or can be expected to continue, indefinitely; and
- constitutes a substantial handicap to the ability of the individual to function in society; or
- results in a significant sub-average general intellectual functioning with concurrent deficits in adaptive behavior which are manifested during the developmental period. Individuals of borderline intelligence may be considered to have mental retardation if there is also serious impairment of adaptive behavior.

Intellectual/developmental disabilities Nurse Association (DDNA) – is a professional organization for nurses serving individuals with intellectual/developmental disabilities. It was incorporated in 1992 to meet the professional needs of nurses in this field.

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) – a manual prepared and distributed by the American Psychiatric Association that describes known behavioral health disorders.

Direct Care Staff – Employees assisting individuals with daily activities.

Disability Law Project – A legal service available to disabled individuals.

Dually Diagnosed – Co-occurring illnesses that may include mental illness, mental retardation or substance abuse.

Embreeville Class Members – Individuals who are named beneficiaries of the Embreeville Class Action lawsuit. The Commonwealth and the individual counties are federally mandated to follow the stipulations of the court order.

Everyday Lives – A philosophy that affords all individuals the opportunity to enjoy a fulfilling life regardless of their disability.

Fair Hearing – A legal process for individuals enrolled in the Medicaid Waiver programs who elect to exercise their rights of due process through a hearing on the merits of their claim.

Family Living/Life Sharing – Type of Community Living Arrangement for an individual with intellectual/developmental disability who lives with an unrelated person. The level of supervision they receive is based on their individual needs, now known as “Family Living Homes”.

Family Support Services – Services provided to families and individuals with intellectual/developmental disabilities who live on their own or in their family home as they request.

Fee for Service – A method by which services may be purchased and reimbursed.

Grievance – A formal complaint by individuals with a developmental disability, or persons acting on their behalf, about an aspect of the program or an employee of the program.

Group Home – Typically a provider owned or operated home located in the community serving one or more individuals with intellectual/developmental disabilities or mental illness.

Guardian – Person responsible for an individual under the age of 18.

Health Care Quality Unit (HCQU)-A regional health care support system for individuals with intellectual/developmental disabilities consisting of a psychiatrist, behavioral specialist, speech pathologist, nurses and health care technical support staff. This staff offers individualized assistance and supports for people with intellectual/developmental disabilities and their families, agency-based supports, community health care support and program and policy development through training, community health care reviews, clinical reviews, consultation, monitoring and technical assistance. There are eight HCQUs in Pennsylvania.

Health Care Technical Assistant (HCTA) - support staff from the HCQU assigned to facilitate managed care, durable medical equipment, pharmacy issues and other technical assistance as needed.

Health Insurance Portability & Accountability Act (HIPAA) – A federal law to insure medical privacy and confidentiality.

Health Risk Profile (HRP) – An instrument utilized by HCSIS and designed to screen the overall health of individuals that receive intellectual/developmental disability services. It is completed by a HCQU nurse on a sample of individuals chosen by the Office of Developmental Programs.

Home & Community Services Information System (HCSIS) – A web enabled information system that serves all DPW program offices that support the Home and Community-Based Services Waivers.

Hospice – End of life medical care ordered by a physician.

Human Rights Committee – A committee that addresses consumer's rights. It also reviews ongoing cases where restrictive procedures are being utilized or considered.

Incident Report - A written report of any injury, accident, act of physical aggression, medication irregularities or unusual incident involving an individual with an intellectual/developmental disability.

Independent Monitoring for Quality (IM4Q) – an external monitoring process developed by the Office of Developmental Programs. It is conducted annually on a sample of individuals with intellectual/developmental disabilities to assess the quality of their lives.

Individual Education Plan (IEP) – The plan written by the IEP team (including parents) that specifically describes the programs and services necessary for a free and appropriate education for a student with an identified disability.

Individual Program Plan (IPP) – The plan developed by a developmental programs residential service provider for each individual.

Individual Support Plan (ISP) - A written plan of support and training services for an individual, revised at least annually, which addresses an individual's support needs.

Individual Support Plan Team (ISP team) - A team composed of the individual, case manager, the person's legal guardian, representatives of all current service providers, and advocates or others determined appropriate by the person receiving services.

In-Home Supports – Services rendered to an individual in their own homes, based on identified and agreed upon needs.

Integration - A person with intellectual/developmental disabilities who lives in the community, uses the same community resources that are used by other members of the community, participates in community activities and has contact with other community members.

Intermediate Care Facility for People with Mental Retardation (ICF/MR) – A facility that can be operated by the state or privately and is licensed by the Department of Health. A small ICF/MR facility supports eight or less individuals.

Legal Guardian – Person appointed by the court to be responsible for an individual deemed by the court to be incompetent.

Licensing – Annual review of a providers' compliance to the specific license they hold.

Medical Assistance or Medicaid (MA) – A federal program that pays for medical services and behavioral health services for qualified people. It provides funding for ICF/MR and most home and community based services provided by county programs.

Mental Retardation (MR) - A significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period (considered to be by the 18th birthday). Persons of borderline intelligence may be considered mentally retarded if there is also serious impairment of adaptive behavior.

Monitoring – Oversight of appropriate delivery of an individual's services and supports.

Office of Developmental Programs (ODP) – A state program office within DPW, which sets policy, allocates funds and administers services for persons with intellectual/developmental disabilities.

Office of Medical Assistance Programs (OMAP) - an Office of the Department of Human Services responsible for coordinating Medicaid medical services. OMAP writes and administers the state Medicaid rules for medical services, contracts with providers and maintains records of client eligibility.

Office of Mental Health and Substance Abuse Services (OMHSAS) – State office of the Department of Public Welfare located in Harrisburg that oversees the provision of mental health and substance abuse services administered by the county programs and state hospitals in Pennsylvania.

Pennhurst Class Members – Individuals who are named in the Pennhurst Class Action lawsuit. The Commonwealth and the counties are mandated to follow the stipulations of the court order.

Pennsylvania Association of Resources for People with Mental Retardation (PAR) – A statewide association whose members provide the full range of supports and services to individuals with mental retardation in more than 3,200 locations in Pennsylvania in addition to numerous non-residential and in-home supports.

Pennsylvania Health Law Project – A nationally recognized expert and consultant on access to health care for low-income consumers, the elderly and persons with disabilities.

Pennsylvania Protection & Advocacy (PP&A) – A federally mandated organization to safeguard the rights of persons with mental or physical disabilities.

Person Centered Planning (PCP) – A process that helps individuals identify how they want to live their lives and what supports they need to achieve their desired outcomes.

Philadelphia Coordinated Health Care (PCHC) – PCHC is the local health care quality unit (HCQU) that provides training, consultation and support for health-related issues within the intellectual/developmental disabilities community. PCHC provides service to people residing in Philadelphia, Bucks, Montgomery, Chester, and Delaware Counties.

Physical Restraint – This is the restriction of the movement of an individual or restricting the movement or normal function of a portion of the individual’s body.

Prioritization of Urgency of Need for Services (PUNS) – Current process for categorizing a person’s need for services.

Pre-Admission Screening Resident Review (PASRR) - A federally mandated screening program conducted prior to admission of any individual into a Medicaid certified nursing care facility. The goals are to prevent inappropriate placements of individuals with mental illness and/or intellectual/developmental disabilities diagnosis into nursing care facilities. Another goal is to assure any special services related to those diagnoses are being met.

Priority Population - Individuals with intellectual/developmental disabilities possessing one or more of the following characteristics:

- A medical condition that is serious and could be life threatening; or
- Behavior that poses a significant danger to the individual.

The case manager monitors these individuals monthly.

Provider - A term used when identifying or referring to the non-profit or for profit organization that provides residential and/or employment services to the person with intellectual/developmental disabilities.

Psychotropic Medications (Behavior Medications) - Medication whose prescribed intent is to affect or alter thought processes, mood or behavior. This includes, but is not limited to, anti-psychotic, anti-depressant, anti-anxiety and behavior medications. Because a medication may have many different effects, its classification depends upon its stated, intended effect when prescribed.

Residential Services – Supports and services based on need, provided to an individual in a residential setting so they can continue living in that environment.

Respite Services – A service that provides temporary relief to the person(s) normally responsible for the care and supervision of individuals with intellectual/developmental disabilities. This service is limited to individuals residing in the homes of family, friends, companions, foster homes or domiciliary homes. Service can be overnight (over 24 hours) or temporary (under 24 hours).

Restraints - Restricting an individual through physical, mechanical or chemical means.

Self-Directed Supports-is an approach to delivering services to individuals with intellectual/developmental disabilities and their families. The main goal is to assist the individuals and families with determining the types and duration of supports needed for living the lives they choose.

Self-Injurious Behavior (SIB) - repeated non-accidental behavior initiated by the individual that directly results in physical injury to him or her.

Self-Determination – A person’s right to decide the course of his/her own life and to make decisions affecting it, along with the responsibilities.

Special Needs Unit (SNU) - A resource provided for the members of the Health Maintenance Organizations (HMOs). The SNUs may:

- help members access medical care and services
- help get approvals for medicines and medical services
- resolve conflicts with providers’ offices
- help plan discharges from hospitals
- arrange stays in skilled nursing facilities

State Operated Facility – A facility that is run under the direct auspices of the Office of Developmental Programs. They are: Ebensburg/Altoona, Hamburg, Polk, Selinsgrove, and White Haven.

Supports Coordinator- A person who helps plan, locate, coordinate and monitor supports and services for an individual. They were formerly known as case managers.

Supported Living – a residential service designed for persons capable of living independently with limited staff support. The amount of staff support varies based on the needs of the individual.

“Team Review of Psychotropic Medication” Form – a three-part document prepared for use at the psychiatric appointment required at least every 90 days for those persons with intellectual/developmental disabilities receiving psychiatric medications.

Twenty-Four Hour Residential Services-is a service that provides 24-hour residential support for individuals with intellectual/developmental disabilities.

Insurance and Governmental Income Definitions

Dually Eligible - People who are eligible for both Medicare and Medicaid. Medicare becomes the primary payor, but these individuals are entitled to the more comprehensive benefits of Medicaid.

Health Maintenance Organization (HMO) - A name for an organization developed to deliver managed health care. This organization accepts a capitated payment (an amount per month per member) and agrees to provide all health services needed that month by that member (within certain contract limits). The organization may be a not-for-profit organization or a for profit business. The organization develops a network of providers (the panel) to provide the services and provides a level of quality assurance and member services, such as patient education, customer services, etc. The basic concept is that being responsible for the total costs and total care, the organization will “manage” the health care efficiently and effectively. There frequently is a stronger emphasis on prevention.

Managed Care Organization (MCO) - see HMO

Medicaid/Medical Assistance (MA) – This is a funding source from the federal government that was originally intended to provide health care for people with low incomes. Medicaid is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law (this includes persons with disabilities). Medicaid does not pay money to you; instead, it sends payments directly to your health care provider. Medicaid is a state administered program and each state sets its own guidelines regarding eligibility and services. The state is required to provide a significant portion of the funds.

Medicare – This is a health insurance program funded through the federal government for people who have worked, (or their dependents), have paid benefits, and are now elderly or disabled. It is funded through federal payroll deductions. The benefits are more limited than Medicaid.

Primary Care Physician/Practitioner (PCP) – A PCP is a health care provider that provides routine health care. PCPs are required to provide access 24 hours per day, 7 days a week. Most PCPs are family physicians, pediatricians, internists, or nurse practitioners. Most managed care plans require a referral from the PCP for access to specialists.

Social Security Benefit (SSB) – This is income from the federal government for workers who are now older or are disabled and their dependents (adult children with disabilities or the spouse). Eligibility for SSB (either SSDI or SS) entitles a person for eligibility in Medicare, but the income may be too high to retain eligibility in Medicaid.

Social Security Disability Income (SSDI) – This is a disability insurance plan from the federal government for workers who become disabled or for dependents who are disabled if the worker/parent is also disabled or elderly. Eligibility for SSDI entitles a person for eligibility in Medicare, but the income may be too high to retain eligibility in Medicaid.

Supplemental Security Income (SSI) – Federal cash benefits and Medicare coverage to people unable to work for a year or more because of disability.

Temporary Aid for Needy Families (TANF) - Previously known as “Aid for Families with Dependent Children” (AFDC) or more commonly “welfare”. TANF provides income assistance with numerous restrictions to families with children. This is usually accessed through Adult and Family Services (AFS)

Waiver – An official approval to deviate from the standard practice of use of Federal Funds. In Pennsylvania, the Office of Developmental Programs has a number of “waivers” that allow Medicaid funds to pay for services for people in the community rather than institutional settings.