Department of Health and Mental Hygiene

Mortality Review Committee

Annual Report

Calendar Year 2006

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Secretary

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I. THE MORTALITY REVIEW COMMITTEE

The Mortality Review Committee (MRC) was established in the Department of Health and Mental Hygiene (DHMH) through legislation effective October 2000, and codified in Maryland Annotated Code, Health General Article § 5-801 through §5-810. As originally enacted, the statute focused on the examination of deaths of individuals in programs or facilities operated or licensed by the Developmental Disabilities Administration (DDA). Subsequently, in 2001, the statute was amended to also require the MRC to review deaths of individuals in facilities or programs operated or licensed by the Mental Hygiene Administration (MHA). This annual report of the Committee encompasses 2006, the fifth calendar year of the Committee's activities. Subsequent annual reports will be published at the conclusion of each calendar year.

The purpose of the Committee is to prevent avoidable deaths and to improve the quality of care provided to persons with developmental disabilities or mental illnesses. To achieve this purpose the Committee performs the following duties:

1. Evaluates causes or factors contributing to deaths reviewable under the statute;
2. Identifies patterns and systemic problems, and ensures consistency in the review process; and
3. Makes recommendations to the Secretary to prevent avoidable deaths and improve quality of care.

Members of the Committee are appointed by the Secretary and include a licensed physician board certified in an appropriate specialty, a psychopharmacologist, a licensed physician on staff with the Department of Health and Mental Hygiene (DHMH), two specialists, one in the field of developmental disabilities and the other in the field of mental illness, a licensed provider of community services for persons with developmental disabilities, a licensed provider of community services for persons with mental illness, two consumers, one with developmental disabilities and the other with mental illness, two family members, one representing a consumer with developmental disabilities and the other representing a consumer with mental illness, the Deputy Secretary of Public Health or the Deputy Secretary's Designee, the Director of the Office of Health Care Quality (OHCQ), a licensed physician representative from the medical examiner's office, a licensed nurse who works with persons with developmental disabilities in a program operated by a State licensed provider in the community, one member of an advocacy group for persons with developmental disabilities, and two members of advocacy groups, one for persons with developmental disabilities and the other for persons with mental illnesses.

The terms of the members are determined at the time of appointment. The terms range from one to three years. A member may not serve for more than two consecutive full terms. The Secretary may remove any member of the Committee for good cause. Members do not receive compensation for service on the Committee.

The Mortality Review Committee meets monthly. A majority of the members of the Committee must be present to vote on decisions related to cases reviewed. The Director of the Office of Health Care Quality does not vote on the disposition of an individual death case previously reviewed by the Office of Health Care Quality. Meetings of the Committee are closed to the public and all deliberations are confidential. All records or files of the Committee, its deliberations, findings, recommendations, and database are confidential . Members may not disclose what transpired at a meeting and are not allowed to communicate directly with a provider, a State Facility Director, a family member, or guardian of the individual who is the subject of a death review. Mortality Review Committee members have immunity from liability

for any action as a member of the Committee or for giving information to, participating in, or contributing to the function of the Committee or its subcommittee.

II. REPORTING REQUIREMENTS

The Mortality Review Committee is required to prepare a report for public distribution at least once a year. The annual report must include aggregate information that sets forth the numbers of deaths reviewed, the age of the deceased, causes and circumstances of death, a summary of the Committee's activities, and summary of findings.

In addition to the annual report for public distribution, the Committee or its subcommittee may, in its discretion, at any time issue preliminary findings or make preliminary recommendations to the Secretary or the Director of the Office of Health Care Quality. The preliminary findings or recommendations are confidential and not discoverable or admissible.[1]

III. THE DEATH REVIEW PROCESS

The Mortality Review Committee is one link in the process of review of deaths in the programs and facilities licensed or operated by the Developmental Disabilities and Mental Hygiene Administrations. The review process begins with a report of a death to the Office of Health Care Quality (OHCQ) and other appropriate agencies. The Developmental Disabilities and Mental Hygiene Administrations both have reporting requirements for deaths in their programs and facilities governed by statute or policy.

The Developmental Disabilities Administration issued a *Policy on Reportable Incidents and Investigations* which became effective July 29, 1999.[2] The purpose of the policy is to protect individuals from harm and to enhance the quality of services provided to them. The policy applies to all State Residential Centers (SRCs) and community-based agencies licensed by the DDA. [3] All deaths in entities covered by the policy must be reported to the following entities:

- The Office of Health Care Quality (OHCQ)
- Developmental Disabilities Administration (DDA) regional office
- Developmental Disabilities Administration (DDA) headquarters
- Family/legal guardian/advocate(s)
- Case manager/resource coordinator
- State protection and advocacy agency (Maryland Disability Law Center)
- Local health department, and
- Police

The Mental Hygiene Administration policy on reporting of deaths in a State funded or operated program or facility is governed by Maryland Annotated Code Article Health General §10-714 (2000). This policy applies to all State-funded or operated facilities and community-

[1] Md. Health – General Code Ann. §5-809; Md. Health – Occupations Code Ann. §14 –501 (2001).
[2] The *Policy on Reportable Incidents and Investigations* was revised and reissued in December 2001, April 2003, October 2003, July 2005, July 2006, and August 2006.
[3] The reporting requirements also apply to those agencies operating by waiver under Md. Health –General Code Ann. § 7-903 (b) (2000).

based agencies receiving State funds. All deaths in entities covered by the policy must be reported to the following:

- Sheriff, police or chief law enforcement official;
- Director of the Mental Hygiene Administration;
- Health Officer in local jurisdiction; and
- State protection and advocacy agency (Maryland Disability Law Center)

Under the provisions of the statute establishing the Mortality Review Committee, the Office of Health Care Quality performs an investigation of each death of an individual with developmental disabilities or mental illnesses who, at the time of death, resided in, or was receiving services from programs or facilities covered under the statute. The purpose of the death investigation is to determine any deficient practice due to regulatory non-compliance. Two exceptions apply to the OHCQ death investigation: 1) OHCQ may not review the care or services provided in an individual's private home, except to the extent needed to investigate a licensed provider that offered services in the individual's home, and 2) unless a member of the Committee requests a review, the Office of Health Care Quality may choose not to review a death if the circumstances, based on reasonable judgment, are readily explained and require no further investigation.

Once OHCQ completes its investigation, the case is referred to the Mortality Review Committee. The MRC then reviews each death case. The Committee may request additional information and documentation including individual records, service of care records, medical records, discharge summary, autopsy reports, medication administration records, and any deficiency statements and plans of corrections if it determines further investigation is warranted. Once a request for information has been made, a provider of medical care, including dental and mental health care, a state or local government agency and a provider of residential or other services must give access to that information. The Committee may prepare questions for the provider agency, State Facility director or other relevant person, or may request the attendance of the provider, director, or other relevant person at a Committee meeting.

IV. COMMITTEE ACTIVITIES AND STATISTICAL INFORMATION

The MRC was scheduled to meet monthly to review death cases referred by OHCQ. However, the scheduled meetings for August and December were canceled. Therefore the MRC met 10 times in calendar year 2006. The MRC reviewed a total of 194 death cases (48 DDA and 146 MHA) for calendar year 2006. At the close of calendar year 2006, 189 cases were closed and 5 cases remained open for further review (FFR), The MRC also reviewed and closed the 3 FFR cases carried over from calendar year 2005.

Number and distribution of deaths by age group

TABLE 1: NUMBER OF DEATHS REVIEWED IN 2006[1] AND NUMBER OF DEATHS OF INDIVIDUALS RECEIVING DDA OR MHA SERVICES IN 2006 COMPARED TO THE NUMBER OF DEATHS AMONG ALL MARYLANDERS BY AGE GROUP IN 2005

Age Group (years)	Deaths Reviewed by MRC in 2006 (DDA)	Deaths of Individuals Receiving DDA Services in 2006	Deaths reviewed by MRC in 2006 (MHA)	Deaths of Individuals Receiving MHA Services in 2006	Total Deaths in Maryland (2005)[2]
<5 years	0	0	0	0	*610*
5 – 14	0	1	1	4	*112*
15 – 24	2	12	11	6	*662*
25- 34	6	8	12	18	*844*
35 – 44	8	24	24	34	*1,785*
45 – 54	12	35	41	82	*3,678*
55 – 64	8	43	24	46	*5,304*
65 – 74	7	24	17	27	*7,036*
75 – 84	3	8	11	15	*12,135*
85+	2	6	5	7	*11,605*
Not stated	n/a	n/a	0	0	*7*
Total	**48**	**161**	**146**	**239**	***43,778***

Note:

1. *The DDA and MHA cases reviewed may have included deaths that occurred in 2004, 2005, and 2006.*
2. *Data provided by DHMH Vital Statistics Administration; 2006 data not yet available*

Table 1 compared the numbers of death cases reviewed in 2006 and the number of deaths of individual receiving DDA or MHA services during this time period to the number of deaths among all Marylanders in 2005. Data indicated that among all Maryland residents, the majority of deaths occurred were in the age ranges of 75- 84 years, and 85 years and over. In comparison among people with disabilities, the majority of deaths were in the age groups of 45-54 and 55-64 years of age for DDA population, and in the age groups of 45-54 and 55-64 for MHA population, respectively.

Gender and Percent Distribution of Reviewed Deaths

TABLE 2: PERCENT DISTRIBUTION OF DDA AND MHA DEATHS BY GENDER REVIEWED IN 2006

Administration	Percent Distribution-DDA	Percent Distribution-MHA
Male	57%	49%
Female	43%	51%

Note: As of December 30, 2006, the population served by DDA consisted of 57% of male and 43% *of females.*
In calendar year 2006, the population served by MHA consisted of 49%% males, 51% *females, and 13 unknown.*

Location of Death

Table 3 illustrated the number and percent distribution of where deaths occurred.

TABLE 3: NUMBER AND PERCENT DISTRIBUTION OF WHERE DEATHS OCCURRED IN THE CASES REVEIWED IN 2006

Location of Death	# & % Distribution 2006 (DDA)	# & % Distribution 2006 (MHA)
Hospice	2 (4%)	8 (5%)
Hospital	21 (44%)	50 (34%)
Nursing Home	5 (10%)	8 (5%)
Residence	19 (40%)	60 (41%)
1. Alternative Living Unit	*4*	*00*
2. Comm. Supported Living Arrangement	*1*	*00*
3. Individual Family Care home	*0*	*00*
4. Group Home	*0*	*00*
5. Family Home	*8*	*14*
6. State Residential Center	*6*	*00*
7. MHA State Facilities	*0*	*1*
8. MHA –CMH[3]	*0*	*41*
Other[1]	1 (2%)	20 (14%)
Total	**48**	**146**

1. *Including vehicle, hotel, street, etc.*
2. *Total percentage may not add to 100 due to rounding.*
3. *CMH stands for Community Mental Health*

By breaking down the number and percent distribution of where the DDA and MHA deaths occurred, it was found that, of the 48 DDA cases reviewed in 2006, 44% of deaths were pronounced in the hospital, 40% occurred in residential settings, and approximately 10% in nursing homes. Of the 146 MHA cases reviewed this past year, 41% occurred in residential settings (community-based), while another 34% of deaths were pronounced in a general hospital setting, 5% in hospice facility and **5%** occurred in nursing home. 14% of the MHA deaths occurred in other settings including vehicle, street, etc.

Service Type

Table 4 depicted the type of services individuals were receiving prior to death. The DDA services included: family and individual support services (FISS)[4], hospice care, nursing home care, residential services, and vocational and day services. The residential service models include alternative living units (ALU)[5], group homes[6], individual family care homes (IFC)[7], community supported living arrangements (CSLA)[8], State Residential Centers (SRC)[9]. Current vocational

[4] FISS may include, but are not limited to, supports involving: (1) Budgeting; (2) Medication administration; Counseling; (4) Job coaching (COMAR 10.22.06.03).
[5] ALU means a residence owned, leased, or operated by a licensee that (a) Provides residential services for individuals who because of a developmental disability, require specialized living arrangement; (b) Admits not more than 3 individuals; and (c) Provides 10 or more hours of supervision per unit, per week (COMAR 10.22.01.01).
[6] Group Home means a residence owned, leased, or operated by a licensee that: (a) Provides residential services for individuals who, because of a developmental disability, require special living arrangements; (b) Admits at least four, but not more than eight individuals; (c) Provides 10 or more hours of supervision, per week (COMAR 10.22.01.01).
[7] IFC means a private, single family residence which provides a home for up to three individuals with developmental disabilities, who are unrelated to the care provider (COMAR 10.22.01.01).
[8] CSLA means services to assist an individual in non-vocational activities necessary to enable that individual to live in the individual's own home, apartment, family home or rental unit with (i) no more than

and day services program models include supported employment, vocational services, day habilitation, and volunteer work. Those who received residential services or FISS may have received vocational and day services at the same time. The MHA cases that were reviewed in 2005 included the deaths of individuals who had received Mental Hygiene Administration (MHA) facilities' residential services and community mental health services.

TABLE 4: TYPE OF SERVICES RECEIVED PRIOR TO DEATH

Type of Services Received Prior to Death	Percentage 2002 (DD only)	Percentage 2003 (DD & MH)	Percentage 2004 (DD & MH)	Percentage 2005 (DD & MH)	Percentage 2006 (DD & MH)
DDA Services	***142 (100%)***	***180 (94%)***	***179 (80%)***	***88 (42%)***	***48 (25%)***
FISS (Family and Individual Support Service)*	17 (12%)	32 (17 %)	16 (7%)	9 (4%)	10 (5%)
Hospice Care	12 (8%)	21 (11%)	22 (10%)	11 (5%)	7 (4%)
Nursing Home Care	12 (8%)	23 (12%)	13 (6%)	7 (3%)	7 (4%)
Residential Services:	87 (61%)	96 (50%)	102 (46%)	54 (26%)	24 (12%)
1. ALU	*27*	*24*	*50*	*21*	*10*
2. CSLA	*8*	*16*	*11*	*5*	*1*
3. IFC	*4*	*5*	*7*	*1*	*0*
4. Group Home	*28*	*43*	*25*	*17*	*0*
5. SRC	*20*	*8*	*9*	*10*	*11*
Vocational and Day Services only	14 (10%)	8 (4%)	26 (11%)	7 (3%)	2
MHA Services	n/a	***11 (6%)***	***44 (20%)***	***122 (58%)***	***146 (75%)***
MHA Facilities	n/a	11	9	15 (7%)	17 (9%)
Community Mental Health	n/a	n/a	35	107 (51%)	129 (66%)
Total	***142***	***191***	***223***	***210***	***194***

As indicated in Table 4, the total 194 cases reviewed in 2006 consisted of 48 (or 25%) deaths of individuals who had received DDA services and 146 (or 75%) of deaths of individuals who had received MHA services. Of the 48 DDA cases, 50% of the reviewed deaths occurred to individuals receiving community residential services followed by those receiving FISS services, and hospice and nursing home services. Hospice care for individuals with developmental disabilities may be provided at a hospice center, a nursing home, family home or a residential setting. Of the 146 MHA cases, a large percentage of the reviewed deaths occurred in community-based settings, closely followed by general hospital settings. Community-based settings include individuals' residences, hotels, street, vehicle, etc.

Cause of Death

TABLE 5 shows the number and percent distribution of the leading causes of death.

TABLE 5: NUMBER AND PERCENT DISTRIBUTION OF LEADING CAUSES OF DEATHS IN CASES REVIEWED IN 2002 THROUGH 2006

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two other non-related recipients of these services; or (ii) members of the same family regardless of their number (COMAR 10.22.01.01).

[9] SRC means a State owned and operated facility for individuals with mental retardation (COMAR 10.22.01.01).

Cause of Death	# & % 2002	# & % 2003	# & % 2004	# & % 2005	# & % 2006
Diseases of the heart	39 (27%)	51 (27%)	50 (22%)	91 (43%)	44 (23%)
Influenza and Pneumonia	31(22%)	33 (17%)	25 (14%)	36 (16%)	17 (9%)
Malignant Neoplasms	14 (10%)	15 (8%)	12 (7%)	37 (17%)	14 (7%)
Other Diseases of Respiratory System	13 (9%)	12 (6%)	13 (6%)	10 (5%)	12 (6%)
Septicemia	11 (8%)	11 (6%)	20 (9%)	15 (7%)	11 (6%)
Accidents	3 (2%)	10 (5%)	18 (8%)	25 (12%)	30 (15%)
Motor Vehicle Accident	*1*	*4*	*1*	*7*	*7*
Nontransport Accident (falls, choking drowning, scalding, etc.)	*2*	*4*	*16*	*10*	*13*
Smoke Inhalation	*0*	*2*	*1*	*1*	*0*
Hypothermia	*0*	*0*	*0*	*1*	*1*
Over Dose		0	*0*	*6*	*9*
Cerebrovascular Disease	2 (1%)	9 (5%)	14 (6%)	7 (3%)	10 (5%)
Epilepsy	7 (5%)	7 (4%)	9 (5%)	3 (1%)	2 (1%)
Nephritis, Nephritic Syndrome & Nephrosis	2 (1%)	4 (2%)	6 (3%)	0 (0%)	0 (0%)
Psychotropic drugs, not otherwise classified	0 (0%)	4 (2%)	0 (0%)	0 (0%)	2 (1%)

The data indicate that out of the death cases reviewed in 2006 disease of the heart remained the leading cause of death among persons with developmental disabilities and mental illnesses was diseases of the heart (7 DDA and 37 MHA cases). Accident ranked as the second leading cause (7 DDA cases and 24 MHA cases) in 2006 and was the 4th leading cause for cases reviewed in 2005. Influenza and pneumonia were remained third leading causes in cases reviewed in 2006 (10 DDA and 7 MHA). Malignant neoplasms were the number 4 leading cause of death for cases reviewed in 2006. They were the second leading cause in cases reviewed in 2005.

TABLE 6: LEADING CAUSES OF THE DEATHS REVIEWED IN 2006 COMPARED TO THE LEADING CAUSES OF DEATH AMONG ALL MARYLANDERS IN 2005

Rank	Leading Causes of the DDA Deaths reviewed by Committee in 2006[1]	Leading Causes of the MHA Deaths Reviewed by Committee in 2006[2]	Leading Causes of death for all Maryland Residents 2005[3]
1	Influenza and Pneumonia	Diseases of the Heart	Disease of the Heart
2	Disease of the heart	Accidents	Malignant Neoplasm
3	Accidents	Malignant Neoplasms/Other Diseases of the Respiratory System (tied)	Cerebrovascular diseases
4	Septicemia	Cerebrovascular Disease/Influenza and Pneumonia (tied)	Chronic Lower Respiratory Diseases
5	Malignant Neoplasm	Septicemia	Diabetes Mellitus
6	Cerebrovascular Diseases	AIDS	Accidents
7	Other Diseases of Respiratory System	Liver Disease	Influenza and Pneumonia
8	Cerebral Palsy	End State Renal Failure/Homicide (tied)	Septicemia
9	Epilepsy	Epilepsy/Multiple Sclerosis/Heat Exhaustion/ Aneurysm (tied)	Alzheimer's Disease
10	Homicide		Nephritis, Nephrotic Syndrome, and Nephrosis

Notes:

1. *The total number of DDA deaths reviewed in 2006 was 48. Deaths may have occurred in 2004, 2005, and 2006;*
2. *The total number of MHA death cases reviewed in 2006 was 146. Deaths may have occurred in* 2003, 2004, 2005 and 2006;
3. *Data provided by DHMH Vital Statistics Administration; 2006 data not yet available.*

TABLE 6 compared the causes of death among people with developmental disabilities and mental illness with the cause of death in the general population. Diseases of the heart were the number one cause of death all Marylanders with malignant neoplasm being the second leading cause of death. For individuals with developmental disabilities, influenza and pneumonia is the number one cause of death. Disease of the heart and accidents were tied being the second leading causes of the death followed by septicemia and malignant neoplasm people with developmental disabilities. Among individuals with mental illness, diseases of the heart were the number one cause of death, followed by accidents. Malignant Neoplasms/Other Diseases of the Respiratory System were tied as the third leading cause of death among individuals with mental illness.

TABLE 7: CASES REVIEWED WHERE SUICIDE WAS THE CAUSE OF DEATH

Suicide Method	Number and Percent Distribution (DDA)	Number and Percent Distribution (MHA)
Drug Overdose	0	7 (5%)
Alcohol Overdose	0	0
Poly Substance Intoxication[1]	0	0
Hanging	0	7 (5%)
Asphyxiation	0	1 (0%)
Jumping[2]	0	2 (1%)
Gun Shot	0	5 (3%)
TOTAL	0	22 (15%)

1. Combination of drug and alcohol intoxication
2. Jumping from bridges, roof tops, etc.

TABLE 7 compares cases reviewed where the cause of death was by suicide and breaks down the suicide by method used. This is the first year for this comparison.

Do Not Resuscitate (DNR)

Approximately 63 (32%) individuals had Do Not Resuscitate (DNR) orders at the time of death. Many of the deaths were due to medical complexity and/or terminal conditions such as advanced stage cancer.

TABLE 8: DO NOT RESUSCITATE (DNR)

DNR Authorized by:	2006 (DDA)	2006 (MHA)
Self	1	7
Family/Guardian	18	25
Court	0	0
Surrogate Decision Maker	0	1
Power of Attorney	0	0
Hospice	0	0
Physician	6	1
Unknown	1	3
Total	**26**	**37**

Medication and Dosage

TABLE 9 and 10 illustrated the number and percentage of individuals who had received medications from each identified agent class. Individuals may have received medication(s) from more than one class. Of the 194 cases reviewed in 2006, 179 or approximately 90% of the individuals had received central nervous system (CNS) active medications during the month prior to death.

TABLE 9: NUMBER AND PERCENTAGE OF INDIVIDUALS RECEIVING MEDICATIONS FROM EACH CLASS – 2003, 2004, 2005, &2006 DATA INCLUDE BOTH DDA AND MHA CASES THAT WERE REVIEWED

Agent Class	Number & Percentage (2003)	Number & Percentage (2004)	Number & Percentage (2005)	Number & Percentage (2006)
Anticholinergic Agent	Data not collected	14 (6%)	8 (5%)	10 (6%)
Anticonvulsant	49 (48%)	87 (39%)	78 (47%)	79 (44%)
Antidepressant	43 (42%)	69 (31%)	87 (53%)	95 (53%)
Antipsychotic	40 (39%)	65 (29%)	99 (60%)	107 (60%)
Anxiolytics	39 (38%)	16 (7%)	34 (21%)	48 (27%)
Cholinesterase Inhibitor	No data	7 (3%)	6 (4%)	0 (0%)
Hypnotics	5 (5%)	46 (21%)	24 (15%)	29 (16%)
Narcotics	14 (14%)	19 (9%)	18 (11%)	18 (10%)
Stimulant	1 (1%)	0 (0%)	1 (1%)	6 (5%)

TABLE 10: COMPARISON OF NUMBER AND PERCENTAGE OF DDA AND MHA INDIVIDUALS RECEIVING MEDICATIONS FROM EACH CLASS

Agent Class	Number & Percentage (DDA) 2006	Number & Percentage (MHA) 2006
Anticholinergic Agent	3 (8%	7 (5%)
Anticonvulsant	27 (68%)	52 (37%)
Antidepressant	12 (30%)	83 (57%)
Antipsychotic	15 (38%)	92 (63%)
Anxiolytics	7 (18%)	41 (28%)
Cholinesterase Inhibitor	0 (0)	0 (0%)
Hypnotics	5 (13%)	24 (16%)
Narcotics	3 (8%	15 (10%)
Stimulant	0 (0%)	6 (4%)
Total number of individuals	**40**	**139**

TABLE 11: NUMBER AND PERCENT DISTRIBUTION OF INDIVIDUALS RECEIVING MEDICATION(S) FROM THE SAME CLASS; 2002, 2003, 2004, 2005, 2006 INCLUDE BOTH DDA AND MHA CASES THAT WERE REVIEWED

Individuals	# & % Distribution (2002)	# & % Distribution (2003)	# & % Distribution (2004)	# & % Distribution (2005)	# & % Distribution (2006)
Individuals Using 1 Agent From The Same Class	71 (59%)	62 (61%)	109 (66%)	115 (70%)	128 (89%)
Individuals Using 2 Agents From The Same Class	42 (35%)	35 (34%)	44 (27%)	73 (44%)	53 (34%)
Individuals Using 3+ Agents From The Same Class	7 (6%)	5 (5%)	12(7%)	17 (10%)	8 (6%)

TABLE 12: COMPARISON OF NUMBER AND PERCENT DISTRIBUTION OF DDA AND MHA INDIVIDUALS RECEIVING MEDICATION(S) FROM THE SAME CLASS

Individuals	Number and Percent Distribution DDA 2006	Number and Percent Distribution MHA 2006
Individuals Using 1 Agent From The Same Class	31 (78%)	128 (92%)
Individuals Using 2 Agents From The Same Class	7 (18%)	53 (38%)

Table 13, Table 14 and Figure 5 describe the number and percent distribution of individuals who had been on one or more different central nervous system (CNS) active medications.

TABLE 13: NUMBER AND PERCENT DISTRIBUTION OF INDIVIDUALS ON CENTRAL NERVOUS SYSTEM (CNS) ACTIVE MEDICATIONS; 2003, 2004, 2005, and 2006 DATA INCLUDE BOTH DDA AND MHA CASES THAT WERE REVIEWED

Individuals	# & % distribution (2002)	# & % distribution (2003)	# & % distribution (2004)	# & % distribution (2005)	# & % distribution (2006)
Individuals on 1 CNS Active medication	47 (39%)	34 (33%)	42 (26%)	31 (19%)	46 (26%)
Individuals on 2 CNS Active medications	43 (36%)	34 (33%)	60 (37%)	47 (28%)	48 (27%)
Individuals on 3 CNS Active medications	14 (12%)	14 (14%)	33 (20%)	42 (25%)	30 (17%)
Individuals on 4 or more CNS active medications	16 (13%)	20 (20%)	28 (17%)	45 (27%)	55 (31%)

Figure 5 Percent Distribution of Individuals on the Numbers of CNS Active Medications

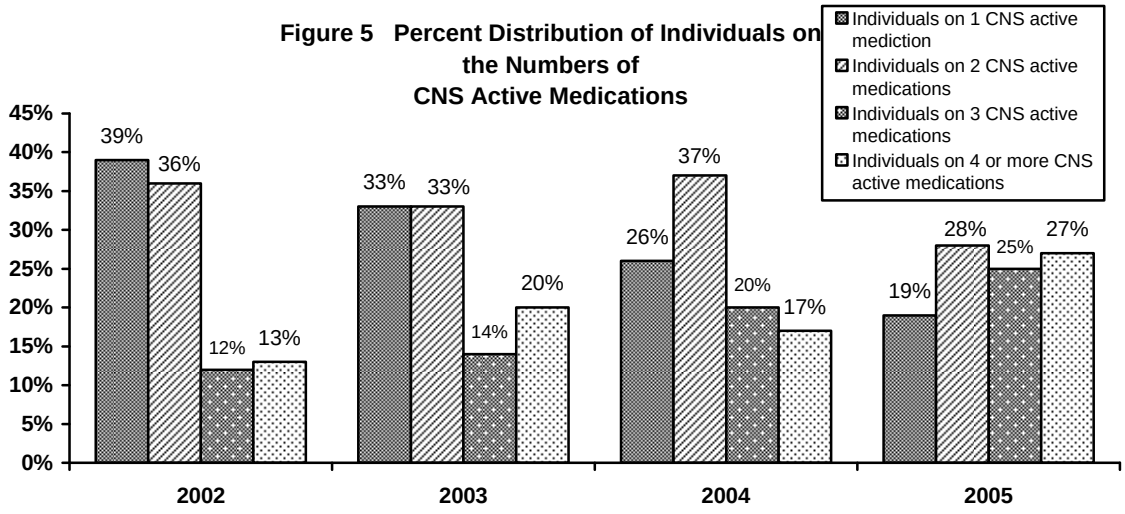

TABLE 14: COMPARISON OF NUMBER AND PERCENT DISTRIBUTION OF DDA AND MHA INDIVIDUALS ON CENTRAL NERVOUS SYSTEM (CNS) ACTIVE MEDICATIONS IN CASES REVIEWED IN 2006

Individuals	Number and Percent Distribution (DDA)	Number and Percent Distribution (MHA)
Individuals on only 1 CNS active medication	18 (45%)	28 (20%)
Individuals on 2 CNS active medications	11 (28%)	37 (27%)
Individuals on 3 CNS active medications	5 (12%)	25 (18%)
Individuals on 4 or more CNS active medications	6(15%)	49 (35%)

TABLE 15 NUMBER OF CASES REFERRED BY MORTALITY REVIEW COMMITTTEE TO OTHER AGENCIES FOR FURTHER EVALUATION

Agencies	Number and Percent of Cases (DDA)	Number and Percent of Cases (MHA)
Assisted Living Unit	1	0
Board of Nursing	1	0
Board of Pharmacists	0	0
Board of Physicians	0	1
DDA	2	0
Hospital Unit	1	1
Licensing Unit	0	0
Long Term Care Unit	2	0
MHA	0	3
Nursing Home Unit	0	0
State Attorney's Office	0	0
Total	**7(18%)**	**5 (3%)**

Table 15 listed the number of cases that were referred to the different licensing board and agencies/unit or State Attorney's office for further investigation, due to concerns of quality of care provided to the individuals.

V. FINDINGS, DISCUSSION AND RECOMMENDATIONS

This report provides data and information that can support the State of Maryland in enhancing services for people with disabilities. Through the comparison of long-term data this report shows how factors contributing to deaths change from year to year and therefore lead to new recommendations for improvement each year.

The Committee represents both the developmental disabilities and the mental illness community, because of the myriad of members' backgrounds excellent discussion and recommendations come forth. The OHCQ investigators work hard to anticipate what the Committee will ask about as well as follow up until the Committee is completely satisfied with an outcome.

During 2006, the Committee was given the additional charge of reviewing quarterly aggregate data from OHCQ on select reportable incidences received from DDA service

providers. Initially this data was a bit delayed in coming to the Committee, but is now being reported on a regular basis. Committee members asked for the data to be organized by provider so as to look for systemic issues. Currently the Committee is evaluating how to move ahead with reviewing the data and the 2007 report will include additional recommendations based on this information.

The following recommendations are based on the findings of this report and concerns of the Committee:

1) Individuals receiving services from DDA and MHA utilize Hospice Care at a very low rate. In 2006, 7 people or 4% of deaths under DDA and 8 people or 5% of deaths under MHA were noted as using hospice at time of death. According to the National Hospice and Palliative Care Organization, "In 2005 approximately one-third of all deaths in the United States were under the care of a hospice program."

Ongoing educational initiatives need to be done to further awareness of hospice care as an option at the end of life. This should occur for individuals in services as well as provider support systems, DDA and MHA staff.

2) End of life legal documentation remains low. In 2006, 26 individuals supported by DDA and 37 supported by MHA had Do Not Resuscitate (DNR) orders. This is lower for DDA compared to 2005 where 45 people had DNR orders and only slightly higher for MHA where 29 people in the previous year had DNR orders.

Additional training and education on the issue of advanced directives and surrogate decision-making needs to be completed. It is particularly important for this information to reach individuals receiving serves, as many of these decisions can be made long before end of life arises and while the ability exists to be involved in these decisions.

It has been noted by the Mortality Review Committee over the past couple of years that individuals and their provider agencies are often in need of an independent health care decision maker or advocate. It is recommended that the disability advocacy community and the legal advocacy community be brought together for the purpose of further exploring surrogate decision-making for individuals with intellectual disabilities who have no family available to act in this capacity. These two communities may be able to develop a method of handling this delicate process.

3) Accidents have increased slightly from being the cause of 12% of deaths in 2005 to 16% in 2006. The two areas of notable increase in accidents include, overdose and non-transport accidents. It is interesting to note that accidents are the second leading cause of death for people served by MHA and the third leading cause of deaths of people served by DDA, when for the general population of the state accidents are the sixth leading cause of death.

Since this increase is very slight, it is simply recommended that it be observed in future years to ensure it does not continue to rise.

4) The Choking Sub-Committee has realized that the issue at hand spans further investigation than originally anticipated. Therefore, it is suggested that a Workgroup with individuals representing OHCQ, DDA, MRC, community service providers and the nursing community be organized to finalize recommendations. This group would meet twice by the end of 2007 and be accompanied by a facilitator who would structure the meetings with an outcome of final recommendations. The following are many recommendations that may be selected by the Workgroup:

- Develop a list by region of state approved Speech Language Pathologists (SLP), Occupational Therapists (OT) and Physical Therapists (PT) that could work with providers to evaluate and make recommendations for the care of individuals with dysphasia. Also create a list of positioning and wheelchair design specialists in each DDA Region. Both lists should be distributed to community providers and State Residential Centers.
- Identify one DDA 'official' Speech-Language Pathologist (possibly a state employee) that providers could utilize for one-time questions about their consumers or immediate/acute strategies for dealing with individuals with dysphasia.
- Encourage DDA to host regional trainings on Choking Prevention. Including the following:
    - A behavioral specialist who can advise on how to support behavioral issues that can lead to choking, like food stuffing. Must be an individual who utilizes best practices in developing behavior plans.
    - An expert on wheelchair positioning and mealtime positioning.
    - A representative from the American Speech Language-Hearing Association (ASHA) to speak on the dysphasia issue.
- Teams should be made aware that wheelchairs can be designed to maintain postures to minimize aspiration and support healthy eating. Distribute pointers on writing to Medicaid for a new wheelchair or seating equipment that will increase safety while eating. The objective is to be able to get these items funded within a reasonable amount of time. Perhaps work with Medicaid Office on what key items they need to see when reviewing these requests. Ask a few people who have been successful at obtaining needed equipment to draft a sample request showing why an item is needed and what might occur if they do not get said item.
- Develop a standard that identifies threshold signs and symptoms that would trigger the necessity of a consumer being evaluated by an SLP for dysphagia. Develop an easy to read small poster on the signs of dysphasia that could be posted or at least reviewed in training of staff. Include in the yearly OSHA presentations dysphagia and related swallowing difficulties as a safety and prevention issue.
- Have the MRC enabling statute changed to include an SLP on the MRC.
- Meet with staff of the Kennedy Krieger Institute Feeding Disorders Clinic to discuss their resources and experience. Meet with a SLP from ASHA and a nutritionist. Possibly have both organizations come to an MRC meeting and discuss choking issues.
- Review statistics from OHCQ on choking related deaths (Aspiration Pneumonia) and hospitalizations to have solid numbers for future reports.

- Develop ways community providers and State Residential Centers can address the 5 leading causes of aspiration pneumonia: dependent feeding, dependent oral hygiene, missing teeth, multiple medications and tube feeding. Explore what else can be done to reduce these factors.
- Increase understanding of the Child and Adult Care Food Program (Standard 4.028) and possibly recommend the development of sample menus for mechanical soft and puree diets as well as thicken liquids.
- Considerations for provider agencies supporting individuals with dysphasia
    - Encourage the evaluation for and possible utilization of the National Dysphasia Diet for consumers that have been identified with dysphasia.
    - Require the teams supporting individuals with dysphasia to include in their IPs reference to individual specific training in swallowing and swallowing disorders by direct care staff involved with their care.
    - COMAR regulation 10.22.02.13 (C) stipulates responsibility for providing medical information when consumers are hospitalized. When consumers with dysphasia are hospitalized we should encourage providers to make a special effort to clearly identify this diagnosis to hospitals generally and Emergency Rooms, ICUs and floor nurse(s) specifically. Specifics of the diets of dysphasia-diagnosed individuals should be clearly reported to hospitals and hospital staffs.
    - Encourage teams in specifying individual needs, particularly in behavior plans, to define for direct care staff in lay-person understandable words definitions of diet preparation terms such as “regular”, “bite-size”, “pureed”, “mechanical soft”, “chopped”, “total ground diet” and liquid consistencies.
- Nurses that work with individuals with developmental disabilities should be required to take training on swallowing and swallowing disorders. Encourage or suggest to DDA that this training be included in the regional Delegating Nurse training.

VI. APPENDIX

MORTALITY REVIEW COMMITTEE MEMBERS

Committee Chair:

• Nicole Brandt, Pharm D., CGP, BCPP - University of Maryland – School of Pharmacy

Committee Members:

• Sarah Basehart, Assistant Director of The Arc of Maryland

• Allison Del Bene Davis, RN., MS., Director of Nursing – Arc of Anne Arundel County

• Tracey DeShields, Director of Public Health Policy - DHMH

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▪ Deana Krizan, Director of Public Policy - Mental Health Association of Maryland

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• Evan Mortimer, MD, Medical Director of Family Planning and Reproductive Health – DHMH

▪ Linda Morrell, Self Advocate

• Cindy Ostrowski, APRN, BC, Program Director - St. Luke's House, Inc

• Roger Peele, MD, Psychiatrist – Montgomery County

• Keith R. Peterson, CEO – Penn Mar Organization, Inc.

•Joanna Pierson, Ph.D., Executive Director – The Arc of Frederick County, Inc.

• Mary Ripple, M.D. Deputy Chief Medical Examiner – Office of the Chief Medical Examiner

• Joan Rumenap, MBA, Director of Special Projects – Abilities Network

• Tracy Wright, Self Advocate

▪ Phyllis Zolotorrow – Family Member

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