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Department of Health
and Human Services
Maine People Living
Safe, Healthy and Productive Lives

Paul R. LePage, Governor
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February 6, 2014

Senator Margaret M. Craven, Chair
Representative Richard R. Farnsworth, Chair
Joint Standing Committee on Health and Human Services
#100 State House Station
Augusta, ME 04333-0100

Dear Senator Craven and Representative Farnsworth and Members of the Joint Standing Committee on Health and Human Services:

Attached please find the 2013 Annual Report to the Legislature for the Maine CDC Newborn Hearing Program submitted by the Department of Health and Human Services. This report is required under Title 22 of the M.R.S.A., Chapter 1686. The report discusses the percentages of Maine infants screened, evaluated and being offered and receiving early intervention services and treatment.

Thank you for the opportunity to provide the Joint Committee on Health and Human Services with a report on the activities and accomplishments of the Maine CDC Newborn Hearing Program.

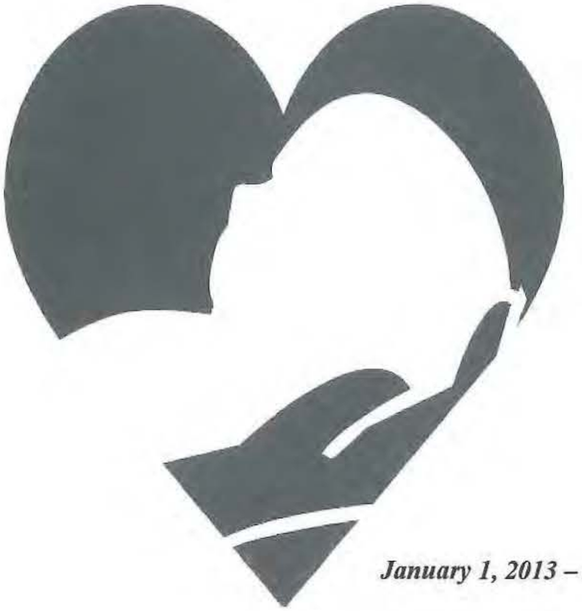
Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Attachment

Maine CDC Newborn Hearing Advisory Board



January 1, 2013 – December 31, 2013

Submitted to the Joint Standing Committee on Health and Human Services

2013 Annual Report

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EXECUTIVE SUMMARY
January 2014

Background

The 119th Maine State Legislature passed Public Law 1999, c.647, adopted under the authority of 22 MSRA c. 1686, §8821-8825 establishing the Maine CDC Newborn Hearing Program (MNHP) within the Department of Health and Human Services. MNHP is currently housed within the Maine Center for Disease Control and Prevention, Division of Population Health, Children with Special Health Needs Program. The intent of the original legislation was "to enable children and their families and caregivers to obtain information regarding hearing screening and evaluation and to learn about treatment and intervention services at the earliest opportunity in order to prevent or mitigate developmental delays and academic failures associated with undetected hearing loss."

Purpose

The overall purpose of the Maine CDC, Newborn Hearing Advisory Board (the Board) is to provide oversight and advice to the Maine CDC Newborn Hearing Program. Each year the Board is required to report to the Joint Committee on Health and Human Services the percentages of infants screened, evaluated and being offered and receiving early intervention services and treatment.

Highlights

This report uses the 2011 data submitted by Maine CDC Newborn Hearing Program to the Federal Center for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Early Hearing Detection and Intervention Program. The 2012 screening data will be available in January 2014.

Screening

- Ninety-eight percent (12,080) of Maine newborns age 1-month or less had a screening for hearing loss in 2011; and
- A total of two percent (281) of Maine newborns were not screened in 2011; the majority of these newborns 60% (169) were home births.

Audiological Evaluation

- Seventy-one percent (201) of Maine infants who did not pass the newborn hearing were referred and received further audiological evaluation in 2011;
- A total of 29.2% (83) of Maine infants did not receive further evaluation in 2011.

Early Intervention

- Forty-five percent (10) infants aged 6-months and under with a confirmed hearing loss were enrolled in early intervention services in 2011; and
- A total of 40.9% (9) infants were receiving no early intervention services.

For more information on MNHP: *Contact Betsy Glencross, Newborn Hearing Coordinator, betsy.glencross@maine.gov or 207-287-8427* www.mainepublichealth.gov/MNHP

Maine CDC Newborn Hearing Advisory Board

Background

The purpose of the Maine CDC Newborn Hearing Program (MNHP) is to support early identification and timely and appropriate intervention for hearing loss. The Maternal and Child Health Bureau, the Joint Committee on Infant Hearing, the American Academy of Pediatrics, and the U.S. Centers for Disease Control and Prevention have provided national goals to each state's Early Hearing Detection and Intervention Programs (EHDI), which in Maine is called the Maine CDC Newborn Hearing Program. These national goals have been established to ensure hearing screening for all newborns no later than one month of age, diagnostic audiological evaluations as early as possible but no later than three months of age for those who do not pass the screening and enrollment in early intervention services, as early as possible but no later than six months of age for those identified with hearing loss.

National Goals

The seven national goals for achieving a comprehensive, coordinated, community-based system of services are:

1. **Screening** - All infants will be screened for hearing loss by one month of age, preferably before hospital discharge.
2. **Diagnostic Audiology** - All infants who screen positive will have a diagnostic audiological evaluation before three months of age.
3. **Early Intervention** - All infants identified with a hearing loss will begin receiving appropriate early intervention services before six months of age.
4. **Family Support** - All infants and children with late onset, progressive, or acquired hearing loss will be identified at the earliest possible time.
5. **Medical Home** - All infants with hearing loss will have a medical home.
6. **Data Management** – Each state will develop a tracking and surveillance system that ensures that babies referred from the screening receive appropriate and timely diagnostic audiological and early intervention services.
7. **Evaluation** – Each state will develop an evaluation plan that improves the overall effectiveness of the service delivery system and meets the needs of families.

State Advisory Board

The Maine Newborn Hearing Advisory Board was created by the 119th Maine State Legislature through the enactment of Public Law 1999,c 647, 22 M.R.S.A. c. 1686.

The Board consists of an odd number of members, appointed by the Governor, including but not limited to: an audiologist, a physician, a speech-language pathologist, a nurse, a certified teacher of the deaf, a person who provides early intervention services to children who are deaf or hard of hearing through the Maine Educational Center for the Deaf and Hard of Hearing, a person who is culturally deaf, a person who is hard-of-hearing or deaf, a parent of a child who is culturally deaf, a parent of child who is hard-of hearing or deaf, a parent of a hearing child and a representative of each of the following: hospitals, health carriers, early childhood special education program under Title 20-A, Chapter 303, and the Department.

The purpose and duties of the Board, as set forth in statute, are to:

- Provide oversight and advice to the Maine CDC Newborn Hearing Program;
- Advise the Commissioner of the Department of Health and Human Services on issues relating to the Program;
- Make recommendations on the procedures for hearing screening, evaluation, treatment and intervention services; and,
- Submit an annual report on the percentages of children being screened and evaluated and those children being offered and receiving intervention and treatment services to the Joint Committee on Health and Human Services.

MNHP Advisory Board Members
December 31, 2013

Audiologist – Eileen Peterson, M.S., FAAA	**Physician** – Christopher Pezzullo, D.O.
Speech-Language Pathologist – Louise Packness, CCC-SLP	**Nurse** – Nola Metcalf, RN-C
Certified teacher of the deaf – Donna Casavant, MED, CAS	**ECFS EI service provider** – Karen Hopkins, M.Ed. CAGS
Culturally deaf person – Catherine Lushman	**Hard of hearing or deaf person** – Romy Spitz, Ph.D. (Co-Chair)
Parent of a child who is culturally deaf – Vacant	**Parent of a hard of hearing or deaf child** – April Morin
Parent of a hearing child – Sarah Pierce Bureau	**Representative of hospitals** – Annette Bowman, RN
Representative of health insurance carriers – Karen Harrison (Co-Chair)	**Representative of CDS** – Kim Appleby
Representative of DHHS – Vacant	**Other** – Carrie Chojnowski, M.S., CCC-SLP, LSLS/Cert. AVT
Other – Harriet Gray, Ph.D.	**Other** – Bethany Picker, MD

The Board is aggressively seeking prospective members to fill the two current vacancies.

Summary of Activities

During 2013, MNHP Advisory Board met three times and reports the following achievements:

- Created a draft Road Map for Families to assist them in the screening, diagnostic and early intervention process.
- Created a draft brochure for pregnant women.
- Began integrating essential data in board discussions and recommendations.
- Identified appropriate candidates for two open board seats: Culturally Deaf Person, and Parent of a Child who is Culturally Deaf. The seat for the Culturally Deaf Person had been vacant for approximately 10 years.

- Created a Quality Improvement Committee that has implemented a systemic review of current data in order to identify areas of challenge and identification of potential solutions, including reviewing the processes and sub-processes through which the program does its work.
- Received training on current topics that impact the program, such as the A.G. Bell Certification of Listening and Spoken Language Specialty and Maine Families Home Visiting Program that is providing further hearing screening at home visits.

Maine CDC Newborn Hearing Program
Summary of the 2011 Data

This report uses 2011 data submitted by the Maine CDC Newborn Hearing Program to the Federal Center for Disease Control and Prevention, National Birth Defects Prevention and Developmental Disabilities, Early Hearing Detection and Intervention Program to describe screening, evaluation, early intervention services and the demographic characteristics of the population. The 2012 screening data will be available in January 2014.

The U.S. Department of Health and Human Services has established national health objectives to be achieved by the end of 2020. These objectives known as Healthy People 2020, includes the following goal related to Newborn Hearing Screening: Increase the proportion of newborns screened for hearing loss by no later than age 1 month, increase the number of newborns with complete audiological evaluation by age 3 months, and increase the number of newborns who are enrolled in appropriate intervention services no later than age 6 months.

The Joint Committee on Infant Hearing recommends the routine monitoring of established benchmarks for the purpose of 1) setting organizational goals; 2) identifying indicators to measure progress toward achieving those objectives; and 3) identifying areas that require a focused quality improvement process.

HEARING SCREENING DATA

The primary goal of the Maine Newborn Hearing Program is to ensure that every child born in Maine is screened for hearing loss. Healthy People 2020 has set the benchmark for screening no later than age 1 month at 90.2%. Maine continues to exceed the goal with a screening rate of 98%.

Objective: Increase the proportion of newborns who are screened for hearing loss no later than age 1 month
Baseline: 82.0 percent of newborn aged 1 month or less had screening for hearing loss in 2007.
Target: 90.2 percent
Achieved: 98.0%

In 2011, the Maine CDC Office of Vital Records reported that there were a total of 12,561 births in Maine. The percentage of Maine newborns that completed a screening by 1 month of age was

98% or 11,778 infants. A total of 284 infants (2%) failed "referred" the initial screen and any subsequent rescreening.

Table 1: Percent and number of infants screened during 2011

Screening						
Total Occurrent Births	**Total Screened**	**Total Pass**	**Total Pass before 1 month of age**	**Total pass after 1 month but before 3 months of age**	**Total pass after 3 months of age**	**Total did not pass "refer"**
12,561	12,280 (97.7%)	11,996 (98%)	11,778 (98%)	176 (1.5%)	42 (0.4%)	284 (2.2%)
Data Source: CDC/NCBDDD/EHDI 2011						

Table 2: Number of infants not screened in 2011

Infants not Screened				
	Total not screened	**Infants died**	**Parents declined**	**Missed**
	281 (2.2%)	69	23	189
Data Source: CDC/NCBDDD/EHDI 2011				

Further analysis of the 189 infants who "missed" the newborn hearing screen reveals the following: 169 were home births; 4 families were unresponsive to any contact made by the Maine CDC Newborn Hearing Program; 5 went to an audiologist and completed testing; and 11 moved or were transferred out of state.

Recommendations

- Continue to educate hospital administrators, nurse managers and other stakeholders to maintain the current screening rate of 98%
- Develop a collaborative relationship with the certified professional midwives to increase the number of families who screen their infants for hearing loss.
- Continue to work with the ME CDC Newborn Hearing Program to improve barriers to stated goals and objectives.

DIAGNOSTIC DATA

According to the National Center for Hearing Assessment and Management (NCHAM) if a baby does not pass the initial newborn hearing screening, the next step in the process is the diagnostic evaluation. The objective is to have the diagnostic tests completed as soon as possible preferably before 3 months of age. The diagnostic evaluation should be performed by a pediatric audiologist with expertise working with infants and children.

Healthy People 2020 have established the following objective related to newborns receiving an audiological evaluation after a "refer" at screening.

Objective: Increase the proportion of newborns who receive audiological evaluation no later than age 3 months for infants who did not pass the hearing screening.
Baseline: 66.0 percent of infants aged 3 months and under who did not pass the hearing screening received audiological evaluation in 2007.
Target: 72.6 percent
Achieved: 53.5%

As reported above the percentage of newborns who failed "referred" the initial screen and any subsequent rescreening was 2.3% or 284 infants. During 2011, a total of 71% (201) infants did receive a diagnostic evaluation. However, only 152 infants (53.5%) received a diagnostic evaluation no later than 3 months of age.

Table 3: The percent and number of infants who received an audiological evaluation during 2011.

Diagnostic Evaluation					
	Total not pass "refer"	**Total receiving diagnostic evaluation before 3 months of age**	**Total receiving diagnostic evaluation after 3 months of age but before 6 months of age**	**Total receiving diagnostic evaluation after 6 months of age**	**Total with no diagnostic evaluation**
	284	152 (53.5%)	18 (6.3%)	31 (10.9%)	83 (29.2%)

Data Source: CDC/NCBDDD/EHDI 2011

Further analysis of the 83 newborns with no diagnosis reveals the following: At the time the data was being reported to the Federal CDC 1 audiological diagnosis was in process; 6 families moved out of state; 7 infants died; 1 family declined any further services; 43 families were contacted by the Maine CDC Newborn Hearing Program (MNHP) but were unresponsive; 7 families could not be contacted by MNHP because of insufficient contact information; and18 were lost to follow-up.

Table 4 shows that 22 infants were identified with a confirmed hearing loss.

Table 4: Percent and number of infants with hearing loss confirmed during 2011

Total identified with hearing loss				
	Total with confirmed hearing loss	**Total hearing loss identified before 3 months of age**	**Total hearing loss identified after 3 months of age but before 6 months of age**	**Total hearing loss identified after 6 months of age**
	22	11 (50%)	3 (13.6%)	8 (36.3%)

Data Source: CDC/NCBDDD/EHDI 2011

Recommendations

- Continue to work with hospitals to ensure that the policies and procedures include infants who "referred" on their newborn screen are referred to a pediatric audiologist for diagnostic evaluation.
- Chapter Champion should work with primary care providers (PCP) to increase awareness of the need for PCPs to ensure that infants who "referred", receive timely diagnostic evaluations.
- Continue to work with the Maine CDC Newborn Hearing Program to improve barriers to stated goals and objectives.

EARLY INTERVENTION DATA

Healthy People 2020 have established the following objective related to infants who are enrolled in early intervention services.

Objective: Increase the proportion of infants with confirmed hearing loss who are enrolled for intervention services no later than age 6 months.
Baseline: 50.0 percent of infants aged 6 months and under with confirmed hearing loss were enrolled for intervention service in 2007.
Target: 55.0 percent
Achieved: 59.0 percent

During 2011, there were a total of 22 infants identified with a confirmed hearing loss. All 22 were referred to Department of Education, Child Development Services, Part C Early Intervention Services. The Maine Newborn Hearing Screening is unable to get information for the Part C on 9 of those children whether or not they are receiving early intervention services.

Table 5: Percent and number of children enrolled in Part C and Non-Part C early intervention services.

Total children enrolled in Part C and Non-Part C					
	Total Enrolled	**Total enrolled before 6 months of age**	**Total after 6 months of age but before 12 months of age**	**Total enrolled after 12 months of age**	**Enrolled but age is unknown**
Part-C	7	5 (71.4%)	1 (14.2%)	0	1 (14.2%)
Non Part-C	6	4 (66.6%)	0	2 (33.3%)	0

Data Source: CDC/NCBDDD/EHDI 2011

Individuals with Disabilities Act (IDEA): Part C - early intervention program for infants and toddlers provides a broad array of services to children with special health needs and developmental disabilities, ages birth through three years of age. In Maine, the Department of Education, Child Development Services is responsible for the Part C services.

Non-Part C services are defined as anyone who is not affiliated with or receives any funds from the Department of Education, IDEA Part C Program. This includes a privately owned early childhood center that offers therapy for disabled children, a not-for profit privately owned speech and hearing clinic that offers therapy for children with hearing loss, a university based early childhood center that offers therapy etc. In other words, any therapy a child is enrolled in that is not managed by Part C can be considered "non-part C".

Recommendation

- Collaborate with Department of Education, Child Development Services to include the Maine CDC Newborn Hearing Program on the release of information form.
- Institute a policy to call families with a confirmed hearing loss to verify early intervention services.
- Continue to work with the Maine CDC Newborn hearing Program to improve barriers to stated goals and objectives.

DEMOGRAPHIC DATA – January 1, 2011 – December 31, 2011

Table 6: 2011 Demographics - Screening Data

	Screening				
	Total Occurrent Births	**Total Pass**	**Total Pass Before 1 Month**	**Total Not Pass**	**Total Not Pass Before 1 Month**
Totals	12561	11996	11778	284	262
Sex					
Male	6450	6141	6022	159	145
Female	6110	5855	5756	125	117
Unknown	1	0	0	0	0
Maternal Age					
<15 years	1	1	1	0	0
15 – 19 years	666	638	623	18	17
20 – 24 years	2950	2854	2793	59	55
25 – 30 years	7050	6717	6606	165	154
35 – 50 years	1892	1784	1753	42	36
> 50 years	2	2	2	0	0
Maternal Education					
< High School	1311	1248	1219	36	34
High School Graduate or GED	4085	3924	3841	104	94
Some College or AA/AS Degree	3055	2924	2871	70	64
College Graduate or above	4075	3875	3822	72	68
Unknown	35	25	25	2	2
Maternal Ethnicity					
Hispanic or Latino	209	201	200	5	5
Not Hispanic or Latino	12342	11787	11570	279	257
Unknown	10	8	8	0	0
Maternal Race					
White (Not Hispanic)	11617	11108	10899	249	228
White (Hispanic	186	180	179	4	4
White (Ethnicity Unknown)	6	5	5	0	0
Black or African American (Not Hispanic)	392	367	361	22	21
Black or African American (Hispanic)	13	13	13	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0	0
Asian	205	196	195	6	6
Native Hawaiians & Other Pacific Islanders	0	0	0	0	0
American Indian & Alaska Natives	108	103	102	2	2
Unknown	21	11	11	1	1
Other	13	13	13	0	0

Data Source: CDC/NCBDDD/EHDI 2011

Table 7: 2011 Demographics - Diagnostic Data

	Diagnosis			
	Normal Hearing	**Normal Hearing Before 3 Months**	**Hearing Loss**	**Hearing Loss Before 3 Months**
Totals	179	141	22	11
Sex				
Male	109	83	10	5
Female	70	58	12	6
Unknown	0	0	0	0
Maternal Age				
<15 years	0	0	0	0
15 – 19 years	12	9	2	1
20 – 24 years	33	23	5	3
25 – 30 years	26	20	3	2
35 – 50 years	26	20	3	2
> 50 years	0	0	0	0
Maternal Education				
< High School	21	15	2	1
High School Graduate or GED	59	41	9	2
Some College or AA/AS Degree	48	42	4	3
College Graduate or above	50	42	7	5
Unknown	1	1	0	0
Maternal Ethnicity				
Hispanic or Latino	3	3	0	0
Not Hispanic or Latino	176	138	22	11
Unknown	0	0	0	0
Maternal Race				
White (Not Hispanic)	155	121	20	9
White (Hispanic	3	3	0	0
White (Ethnicity Unknown)	0	0	0	0
Black or African American (Not Hispanic)	16	12	1	1
Black or African American (Hispanic)	0	0	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0
Asian	4	4	1	1
Native Hawaiians & Other Pacific Islanders	0	0	0	0
American Indian & Alaska Natives	0	0	0	0
Unknown	1	1	0	0
Other	0	0	0	0

Data Source: CDC/NCBDDD/EHDI 2011

Table 8: 2011 Demographic - Early Intervention Data

	Early Intervention			
	Total Enrolled in Part C EI	**Total Enrolled in Part C EI Before 6 Months**	**Total Services Non-Part C EI**	**Total Services Non-Part C EI Before 6 Months**
Totals	7	5	6	4
Sex				
Male	2	1	5	3
Female	5	4	1	1
Unknown	0	0	0	0
Maternal Age				
<15 years	0	0	0	0
15 – 19 years	0	0	1	1
20 – 24 years	3	2	2	2
25 – 30 years	2	2	3	1
35 – 50 years	2	1	0	0
> 50 years	0	0	0	0
Maternal Education				
< High School	1	1	1	0
High School Graduate or GED	1	0	3	2
Some College or AA/AS Degree	3	2	0	0
College Graduate or above	2	2	2	2
Unknown	0	0	0	0
Maternal Ethnicity				
Hispanic or Latino	0	0	0	0
Not Hispanic or Latino	7	5	6	4
Unknown	0	0	0	0
Maternal Race				
White (Not Hispanic)	7	5	6	4
White (Hispanic	0	0	0	0
White (Ethnicity Unknown)	0	0	0	0
Black or African American (Not Hispanic)	0	0	0	0
Black or African American (Hispanic)	0	0	0	0
Black or African American (Ethnicity Unknown)	0	0	0	0
Asian	0	0	0	0
Native Hawaiians & Other Pacific Islanders	0	0	0	0
American Indian & Alaska Natives	0	0	0	0
Unknown	0	0	0	0
Other	0	0	0	0

Data Source: CDC/NCBDDD/EHDI 2011

APPENDIX A: Trend Analysis 2009 – 2011 Screening, Diagnosis and Early Intervention

	2009	**2010**	**2011**
Total Occurrent Births	13353	12812	12561
Total Screened	13020 (98%)	12502 (98%)	12280 (98%)
Total Not Screened	333 (2%)	310 (2%)	281 (2%)
Total Passed	**12653**	**12308**	**11996**
Pass Before 1 Month of Age	12457 (98%)	12117 (98%)	11778 (98%)
Pass After 1 Month but Before 3 Months of Age	157	160	176
Pass After 3 Months of Age	37	30	42
Pass: Age Unknown	2	0	0
Total Not Passed	**367**	**194**	**284**
Not Pass Before 1 Month of Age	355 (97%)	187 (96%)	262 (92%)
Not Pass After 1 Month but Before 3 Months of Age	8	5	14
Not Pass After 3 Months of Age	4	2	6
Not Pass: Age Unknown	0	0	2
Total Not Pass Screening	**367**	**194**	**284**
Total with No Hearing Loss	**107**	**114**	**179**
No Hearing Loss Before 3 Months of Age	87 (81.3%)	85 (74.5%)	141 (79%)
No Hearing Loss After 3 Months but Before 6 months of Age	8	11	15
No Hearing Loss After 6 Months of Age	12	1	23
No Hearing Loss: Age Unknown	0	17	0
Total Hearing Loss	**13**	**17**	**22**
Hearing Loss ID Before 3 Months of Age	8 (62%)	9 (53%)	11 (50%)
Hearing Loss ID After 3 Months but Before 6 Months of Age	4	2	3
Hearing Loss ID After 6 Months of Age	1	6	8
Hearing Loss ID: Age Unknown	0	0	0
Total Cases Hearing Loss	**13**	**17**	**22**
Total Referrals to Part C	**13 (100%)**	**17 (100%)**	**22 (100%)**
Total Enrolled in Part C EI Services	**2**	**6**	**7**
Enrolled Before 6 Months of Age	2 (100%)	4 (67%)	5 (71%)
Enrolled After 6 Months but Before 12 Months of Age	0	2	1
Enrolled After 12 Months of Age	0	0	0
Enrolled: Age Unknown	0	0	1
Total Enrolled in Non-Part C EI Services Only	**0**	**3**	**6**
Services Before 6 Months of Age	0	1	4
Services After 6 Months but Before 12 Months of Age	0	0	0
Services After 12 Months of Age	0	2	2
Services: Age Unknown	0	0	0
Total Not enrolled in EI Services (loss to follow-up)	**11 (85%)**	**7 (41%)**	**9 (41%)**