Final Report

WORKING GROUP TO STUDY THE EFFECTIVENESS AND TIMELINESS OF EARLY IDENTIFICATION AND INTERVENTION FOR CHILDREN WITH HEARING LOSS IN MAINE

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Introduction

The Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine (referred to here as "the Working Group") was initially created pursuant to Resolve 2007, Chapter 133. (See Appendix A) Chapter 133 was passed during the First Regular Session of the 123rd Legislature and directed the Working Group to submit a report to the Second Regular Session of the 123rd Legislature. It also required the Working Group to seek outside funding to fund all costs of the Working Group. Due to unforeseen delays in obtaining the funding and delays in the appointment process, the Working Group was unable to meet during the 2007 interim. Because of the importance of the issues to be addressed by the Working Group, the Legislature passed a Joint Order in January 2008 (Appendix B) which reauthorized the Working Group and directed it to meet during the Second Regular Session and submit its report to the Legislature in March 2008.

The Working Group was comprised of 17 members representing the following interests:

- Three members of the Senate;
- Six members of the House of Representatives;
- One representative of the Maine Academy of Audiology;
- One representative of the Department of Education, Child Development Services;
- One representative of the Warren Center for Communication and Learning;
- One representative of the Maine chapter of the American Academy of Pediatrics;
- One representative of the Maine Speech-Language-Hearing Association;
- The Director of Statewide Educational services for the Maine Educational Center for the Deaf and Hard of Hearing;
- The Executive Director of "Hear ME Now!"; and
- One representative of the Maine Society of Otolaryngology.

The Working Group's charge was to examine issues of access to timely and accurate diagnosis of hearing loss by 3 months of age and to review and assess the processes by which families are informed of their options for communication and for finding providers in the State.

Summary of our work in 2008

The Working Group met three times during the first three months of 2008. In completing our work, we consulted with the Department of Health and Human Services Newborn Hearing Program, Early Childhood and Family Services, Child Development Services, the Children with Special Health Care Needs Program, and the Public Health Nursing Program. In our meetings with these groups, we discussed issues related to screening and evaluation of children, dissemination of information to parents and existing services. We also consulted with the Attorney General's Office in connection with special education rules and examined the current system in Maine as well as the laws and programs of other New England states.

After gathering information about the current system and discussing issues and challenges of the current system, we identified ten key findings and made five recommendations.

Two of our recommendations require legislation in order to be implemented effectively. We have included recommended legislation (Appendix C) to implement those recommendations.

The Working Group makes the following ten findings and five recommendations:

Findings

1) Maine has a multi-faceted system of early identification and intervention for children with hearing loss.

2) While there is no mandatory screening in Maine, hospitals and birthing centers screen newborns for hearing loss and report the screening results in accordance with Maine's mandatory reporting law. The State's screening rate of over 96% is generally in line with the rest of New England.

3) Maine, along with New Hampshire and Vermont, lags behind in the percentage of audiological reports received for infants that did not pass the initial screening. The low rate may be due to lack of follow-up on referrals to professionals or programs for further infant hearing evaluation, under-reporting from audiologists, and other factors.

4) New mandatory reporting requirements for audiologists as well as outreach to audiologist about the requirements may show that more infants actually received audiologist services after referral than currently reported.

5) Outreach, information, intervention and education is available through several programs and agencies including:

    - Maine Educational Center for the Deaf and Hard of Hearing, which includes Early Childhood and Family Services, provides services to support children and their families in making decisions about communication and education including home visits;

    - Child Development Services, which by state and federal law is required to identify, locate, evaluate and provide services to children with disabilities under the age of 5 years. The CDS system includes 16 regional sites, a state office and the Maine Advisory Council;

- Maine Newborn Hearing Program, which was established to enable children and their families to obtain information about screening and intervention and is authorized to implement a tracking system. It receives oversight and input from the Newborn Hearing Screening Advisory Board;

- Children with Special Health Care Needs Program, which supports children and their families with obtaining and coordinating medical care related to special needs including hearing loss; and

- The Public Health Nursing Program, which has a mission to provide expertise and leadership to improve the health of populations. The program supports children and their families through a variety of community and home-based services.

6) Strong communication between families, state programs, schools and health care professionals, including audiologists and pediatricians, is a key factor in ensuring effective and timely identification, intervention and follow-up related to hearing loss.

7) Barriers to early identification and intervention may include gaps in follow-up, transportation issues, need for physician education on the 1,3,6 model, decentralized referral system and services, multiple service providers, incomplete information needed to facilitate referrals and connect children with services, a fragmented notification and referral system, a shortage of regional providers in certain areas of the state, a need for better interagency coordination, and financial resource issues.

8) There is no uniform reporting system in place to notify the Department of Education CDS offices of children with hearing loss.

9) In 2006, 330 newborns in Maine did not pass newborn hearing screening. Diagnostic audiological test results from audiologists were reported back to MNHP for only 112 babies. The remaining 218 were lost to follow up. It is unknown if these children received the diagnostic testing and went unreported by audiologists, or if they never received further testing.

10) There is a lack of sufficient numbers of audiologists willing and specifically trained to provide the required audiological services.

Recommendations

1) At this time, we do not recommend mandatory screening of newborns for hearing loss by birthing hospitals and birthing centers. We have found that birthing hospitals and birthing centers are currently screening newborns for hearing loss on a voluntary basis. However, we believe the number of newborns being

screened should continue to be monitored by the Maine Newborn Hearing Program and if birthing hospitals and birthing centers discontinue or significantly reduce their voluntary screening of newborns, the Legislature should reconsider mandating newborn hearing loss screening by those hospitals and birthing centers.

2) We encourage the Maine Newborn Hearing Program, established within the Department of Health and Human Services, to inform birthing hospitals and birthing centers that Child Development Services (CDS) is one of the community resources available to parents for the continued evaluation of hearing loss in newborns and that this information should be included by the birthing hospital or birthing center in the educational materials provided to parents of newborns identified as having or being at risk of developing hearing loss.

3) We recommend that, upon the approval of a parent or legal guardian of a newborn identified as having or being at risk of developing hearing loss, the birthing hospital or birthing center in which the child was born schedule follow-up visits with an audiologist for the newborn. We recommend that those follow-up appointments be made prior to discharging the newborn and that the hospital or birthing center notify the newborn's primary care provider in writing of such a referral within 45 days after discharging the newborn. This recommendation requires a statutory change, which is included in our recommended legislation.

4) We support the Maine Newborn Hearing Program's study of the barriers to access to audiologists for the continued evaluation of hearing loss in newborns. We recommend that the Maine Newborn Hearing Program report the results of this study to the joint standing committee having jurisdiction over health and human service matters. We have included unallocated language in our recommended legislation requiring that this report be provided to the committee by March 31, 2009.

5) We recommend that this report and our recommended legislation be referred to the Joint Standing Committee on Health and Human Services for consideration and action in the Second Regular Session of the 123rd Legislature.

APPENDIX A

Resolve 2007, Chapter 133

Resolve, To Establish a Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine

Resolve
123rd Legislature
First Regular Session
Chapter 133
H.P. 881 - L.D. 1239

Resolve, To Establish a Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine

Emergency preamble. Whereas, acts and resolves of the Legislature do not become effective until 90 days after adjournment unless enacted as emergencies; and

Whereas, this resolve establishes a working group to study the effectiveness and timeliness of early identification and intervention for children with hearing loss; and

Whereas, this resolve requires that the working group submit a report and recommended legislation by December 7, 2007, and the work needs to begin as soon as possible; and

Whereas, the study must be initiated before the 90-day period expires in order that the study may be completed and a report submitted in time for submission to the next legislative session; and

Whereas, in the judgment of the Legislature, these facts create an emergency within the meaning of the Constitution of Maine and require the following legislation as immediately necessary for the preservation of the public peace, health and safety; now, therefore, be it

Sec. 1 Working group established. Resolved: That the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine, referred to in this resolve as "the working group," is established; and be it further

Sec. 2 Working group membership. Resolved: That the working group consists of 17 members appointed as follows:

1. The following members appointed by the President of the Senate:
A. Three members of the Senate. When making the appointments, the President of the Senate shall give preference to members of each of the 2 major political parties and to members of the Joint Standing Committee on Education and Cultural Affairs and to members of the Joint Standing Committee on Health and Human Services;
B. One representative of the Maine Academy of Audiology;
C. One representative of the Department of Education, Child Development Services;
D. One representative of the Warren Center for Communication and Learning; and
E. One representative of the Maine chapter of the American Academy of Pediatrics;

and

2. The following members appointed by the Speaker of the House of Representatives:

A. Six members of the House of Representatives. When making the appointments, the Speaker of the House shall give preference to members of each of the 2 major political parties and to members of the Joint Standing Committee on Education and Cultural Affairs and to members of the Joint Standing Committee on Health and Human Services;

B. One representative of the Maine Speech-Language-Hearing Association;

C. The Director of Statewide Educational Services for the Maine Educational Center for the Deaf and Hard of Hearing or the director's designee;

D. The Executive Director of hear ME now! or the director's designee; and

E. One representative of the Maine Society of Otolaryngology; and be it further

Sec. 3 Chairs. Resolved: That the first-named Senate member is the Senate chair of the working group and the first-named House of Representatives member is the House chair of the working group; and be it further

Sec. 4 Appointments. Resolved: That all appointments must be made no later than 30 days following the effective date of this resolve. The appointing authorities shall notify the Executive Director of the Legislative Council once all appointments have been completed. Within 15 days after appointment of all members, the chairs shall call and convene the first meeting of the working group, which must be no later than 30 days after the appointment of all members is complete; and be it further

Sec. 5 Duties. Resolved: That the working group shall examine issues of access to timely and accurate diagnosis of hearing loss by 3 months of age, and review and assess the processes by which families are informed of their options for communication and for finding providers in the State.

In examining these issues, the working group shall specifically examine:

1. The definition of a "highly qualified provider" in various professions serving this population;

2. The operation and effectiveness of existing programs and resources for families who have children who have been identified as having hearing loss;

3. Opportunities for coordination to maximize the effects of available resources;

4. The need for state or private programs to supplement state programs or to enable existing programs to serve a greater portion of those eligible;

5. Techniques to use resources in new ways or new combinations that have the

potential for easing the burden on current providers and enhancing the training of current and new providers to enable equal access to highly qualified providers to all children statewide;

6. The effects of limited resources for diagnostic testing and poor reimbursement rates; and

7. Programs and techniques that are employed in other states or countries; and be it further

Sec. 6 Staff assistance. Resolved: That the Legislative Council shall provide necessary staffing services to the working group; and be it further

Sec. 7 Compensation. Resolved: That the legislative members of the working group are entitled to receive the legislative per diem, as defined in the Maine Revised Statutes, Title 3, section 2, and reimbursement for travel and other necessary expenses related to their attendance at authorized meetings of the working group. Public members not otherwise compensated by their employers or other entities that they represent are entitled to receive reimbursement of necessary expenses and, upon a demonstration of financial hardship, a per diem equal to the legislative per diem for their attendance at authorized meetings of the working group; and be it further

Sec. 8 Report. Resolved: That, no later than December 7, 2007, the working group shall submit a report that includes its findings and recommendations, including suggested legislation, to the Second Regular Session of the 123rd Legislature. The working group is not authorized to introduce legislation; and be it further

Sec. 9 Outside funding. Resolved: That the working group shall seek outside funding to fully fund all costs of the working group. If sufficient outside funding has not been received by the working group by October 1, 2007 to fully fund all costs of the working group, no meetings are authorized and no expenses of any kind may be incurred or reimbursed; and be it further

Sec. 10 Appropriations and allocations. Resolved: That the following appropriations and allocations are made.

LEGISLATURE

Study Commissions - Funding 0444

Initiative: Allocates funds for the per diem and expenses of the Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine.

OTHER SPECIAL REVENUE FUNDS	**2007-08**	**2008-09**
Personal Services	$1,980	$0

All Other	$7,510	$0
OTHER SPECIAL REVENUE FUNDS TOTAL	$9,490	$0

Emergency clause. In view of the emergency cited in the preamble, this legislation takes effect when approved.

Effective June 27, 2007.

APPENDIX B

H.P. 1513

Joint Order establishing the Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine

ORDERED, the Senate concurring, that the Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine is established as follows.

1. Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine established. The Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine, referred to in this order as "the working group," is established.

2. Membership. The working group consists of 17 members, appointed as follows:

A. The following members appointed by the President of the Senate:

(1) Three members of the Senate. When making the appointments, the President of the Senate shall give preference to members of each of the 2 major political parties and to members of the Joint Standing Committee on Education and Cultural Affairs and to members of the Joint Standing Committee on Health and Human Services;
(2) One representative of the Maine Academy of Audiology;
(3) One representative of the Department of Education, Child Development Services;
(4) One representative of the Warren Center for Communication and Learning; and
(5) One representative of the Maine chapter of the American Academy of Pediatrics; and

B. The following members appointed by the Speaker of the House:
(1) Six members of the House of Representatives. When making the appointments, the Speaker of the House shall give preference to members of each of the 2 major political parties and to members of the Joint Standing Committee on Education and Cultural Affairs and to members of the Joint Standing Committee on Health and Human Services;
(2) One representative of the Maine Speech-Language-Hearing Association;
(3) The Director of Statewide Educational Services for the Maine Educational Center for the Deaf and Hard of Hearing or the director's designee;
(4) The Executive Director of hear ME now! or the director's designee; and
(5) One representative of the Maine Society of Otolaryngology.

3. Working group chairs. The first-named Senator is the Senate chair of the working group and the first-named member of the House is the House chair of the working group.

4. Appointments. Those persons appointed in 2007 by the President of the Senate and the Speaker of the House to serve as members of the Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine as established by Resolve 2007, chapter 133, including the Senator and the member of the House appointed to serve as the chairs of that study, are appointed to serve as members of the working group established in this order.

5. Duties. The working group shall examine issues of access to timely and accurate diagnosis of hearing loss by 3 months of age and review and assess the processes by which families are informed of their options for communication and for finding providers in the State. In examining these issues, the working group shall specifically examine:

A. The definition of a "highly qualified provider" in various professions serving this population;

B. The operation and effectiveness of existing programs and resources for families who have children who have been identified as having hearing loss;

C. Opportunities for coordination to maximize the effects of available resources;

D. The need for state or private programs to supplement state programs or to enable existing programs to serve a greater portion of those eligible;

E. Techniques to use resources in new ways or new combinations that have the potential for easing the burden on current providers and enhancing the training of current and new providers to enable equal access to highly qualified providers to all children statewide;

F. The effects of limited resources for diagnostic testing and poor reimbursement rates; and

G. Programs and techniques that are employed in other states or countries.

6. Staff assistance. The Legislative Council shall provide necessary staffing services to the working group.

7. Meetings and report. The working group is authorized to meet up to 4 times during the Second Regular Session of the 123rd Legislature and shall submit its report, including suggested legislation, to the Second Regular Session of the 123rd Legislature no later than March 3, 2008.

8. Compensation. The legislative members of the working group are entitled to reimbursement for travel and other necessary expenses related to their attendance at authorized meetings of the working group that are held on days in which the Legislature is not in session. Public members not otherwise compensated by their employers or other entities that they represent are entitled to receive reimbursement of necessary expenses and, upon a demonstration of financial hardship, a per diem equal to the legislative per diem for their attendance at any authorized meetings of the working group.

9. Outside funding. The working group is funded by outside funding received and accepted by the Legislative Council in 2007 for the original purposes of funding the Working Group To Study the Effectiveness and Timeliness of Early Identification and

Intervention for Children with Hearing Loss in Maine as established by Resolve 2007, chapter 133.

APPENDIX C

RECOMMENDED LEGISLATION

AN ACT to Implement the Recommendations of the Working Group To Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss in Maine

An Act to Implement the Recommendations of the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 22 MRSA, §8822, sub-§4-A is enacted to read:

4-A. Follow-up appointment with an audiologist. Upon the approval of a parent or legal guardian of a newborn identified as having or being at risk of developing hearing loss, the birthing hospital or birthing center in which the child was born must schedule the newborn for a follow-up appointment with an audiologist. That follow-up appointment must be scheduled prior to discharge and the hospital or center must notify the newborn's primary care provider in writing of such a referral within 45 days after discharge.

Sec. 2. Report on barriers to access to audiologists. The Newborn Hearing Program, established in Title 22, chapter 1686 of the Maine Revised Statutes, shall report to the joint standing committee of the Legislature having jurisdiction over health and human services matters by March 31, 2009 on the results of its study of barriers to access to audiologists for the continued evaluation of hearing loss in newborns.

SUMMARY

This bill implements the unanimous recommendations of the Working Group to Study the Effectiveness and Timeliness of Early Identification and Intervention for Children with Hearing Loss.

The bill requires, upon the approval of a parent or legal guardian of a newborn identified as having or being at risk of developing hearing loss, the birthing hospital or birthing center in which the child was born to schedule the newborn for a follow-up appointment with an audiologist. That appointment must be scheduled prior to discharge and the birthing hospital or center must notify the newborn's primary care provider in writing of such a referral within 45 days after discharge.

The bill also requires the Newborn Hearing Program within the Department of Health and Human Services to report to the joint standing committee of the Legislature having jurisdiction over health and human services matters by March 31, 2009 on the results of its study of barriers to access to audiologists for the continued evaluation of hearing loss in newborns.