

**Task Force to Study the Needs of Deaf & Hard-of-Hearing Children and
Adolescents
November 20, 2003
Meeting Summary**

Members present: Sen. Betheda Edmonds (co-chair), Rep. Elaine Makas (co-chair), Rep. Richard Brown, Jan DeVinney, Mary Edgerton, Mary Martone, Jenn McCann, Doug Moody, Suzanne Chadwick, Kathy Fries, Stephen Green, Ph.D., Jana Harbaugh, Meryl Troop, Christine Bartlett and Toni Wall

Members absent: Sen. Betty Lou Mitchell, Rita LaBarbera, and Jeannie Shacker

Staff present: Phillip D. McCarthy, Ed.D., Legislative Analyst; Nicole Dube, Legislative Analyst; Betsy Reifman, Interpreter; and Margaret Haberman, Interpreter

I. Introductions

Sen. Edmonds convened the Task Force meeting and asked Task Force members to introduce themselves and make introductory remarks. Following introductions, staff reviewed the meeting guidelines, duties and proposed work plan with the Task Force.

II. Overview of the Current System

The Task Force heard presentations from several agencies and providers regarding the existing network of mental and behavioral health services that are currently available to Deaf and hard-of-hearing children.

Department of Behavioral and Developmental Services (BDS). Meryl Troop, Director, Office of Deaf Services and Multicultural Diversity provided an overview of current Deaf mental health services within BDS. BDS serves a population with a primary mental health or mental retardation diagnosis. Children's Services within the department does not have specialized Deaf services, however the department contracts with Community Counseling Center to provide mental health services to its Deaf population.

Ms. Troop also provided details about a 1997 joint "request for proposal" (RFP) developed by the Department of Mental Health, Mental Retardation and substance Abuse services (precursor to BDS), Department of Education and Department of Human Services to create an in-state therapeutic treatment program for Deaf adolescents with serious emotional disturbances, based on the Western Pennsylvania School for the Deaf and funded by grants available at the time (see white presentation handout). Although there was interest from both in-state and out-of-state providers, and even though the RFP was circulated twice, there was only one proposal submitted by the National Academy for the Deaf, which was rejected due to its high cost and inability to meet certain provisions of the RFP (e.g., clinical and residential requirements).

Community Counseling Center (CCC). Jana Harbaugh and Jenn McCann of the CCC provided an overview of Deaf mental health services provided by their agency (see white presentation handout). CCC provides case management, individual and family therapy and consultative services to Deaf children and their families with a range of behavioral and mental health needs. Their presentation included information on the types of services provided, geographic area covered, demographic data, out-of-state placements, financial issues, agreements with other states and other state models.

Department of Education (DOE). Christine Bartlett, DOE Special Services Consultant, briefed the Task Force on educational services provided by the Department for Deaf and hard-of-hearing children. Each

school administrative unit is required by law to provide school services for special education students ages 3 to 20. DOE approves all out-of-state placements and provides funding for educational services provided for out-of-state placements. In addition, DOE conducts an annual count of children with disabilities on December 1st. While DOE collects data on the category of Deaf students, they do not collect data on Deaf children that have additional mental or behavioral health problems. These “Deaf-plus” children are coded under the category “multiple disability”, making it difficult to determine an accurate number of Deaf children with additional mental health problems and the incidence of the various types of behavioral or emotional health problems.

Governor Baxter School for the Deaf (GBSD) Statewide Outreach and Consulting Services. Angela Bruno, GBSD Public School Outreach Services and Karen Hopkins, GBSD Early Childhood Intervention Services briefed the Task Force on outreach services provided by the GBSD. GBSD offers a Public School Outreach program that provides free consultative services to schools that serve students who are Deaf or hard-of-hearing, to assist service providers with implementing an appropriate and positive educational experience for students in grades K-12. GBSD also offers an Early Childhood and Family Services outreach program that provides free consultative services to Maine families with children ages birth to five who are Deaf, hard-of-hearing or have a suspected hearing loss (see presentation handouts and colored leaflets).

Key points raised during Task Force discussion:

- There is a lack of awareness and coordination among agencies and providers;
- This lack of coordination can result in interruption of service provision and education for children;
- While there is a desire to keep children in the state, Maine does not provide the necessary continuum of mental health services and placements for Deaf and hard-of-hearing children;
- Out-of-state placements make it difficult for families to participate in treatment (travel, increased costs);
- The payment mechanism for out-of-state placements is unwieldy, (separate payments come from DOE for education-related services, from BDS for room and board and from MaineCare for mental health services), making other states more reluctant to accept Maine children into their treatment programs;
- Certain specialty treatment facilities in other states are also concerned about Maine failing to provide payment for services or for paying a different reimbursement rate than the in-state rate (e.g., Massachusetts law prohibits differential Medicaid reimbursement rates for different children);
- Merely providing interpreters to Deaf and hard-of-hearing children through a “hearing” mental health service program does not make these services accessible to Deaf and hard-of-hearing children;
- Services are not provided equitably across geographic regions of the state;
- There is difficulty in recruiting qualified interpreters and “signing” mental health providers to the state;
- To attract and retain Deaf clinicians, Maine needs to have a community of like-minded professionals;
- Increased mainstreaming will result in increased mental health needs of Deaf and hard-of-hearing children and adolescents due to the isolation experienced by these children;
- There is an expectation by BDS that “in-state” agencies providing case management for children placed out-of-state to keep cases open and arrange for “take back” services for out-of-state placements to reintegrate the child into their home, school and community;
- BDS only provides services to children and adolescents who have a “primary diagnosis” (i.e., an emotional and behavioral health problem); and, as a result, a Deaf or hard-of-hearing child must first have a mental health diagnosis;
- Deaf children and adolescents do not receive the benefits of community-based treatments because they are consistently placed in outdated residential treatment models;
- BDS receives a relatively modest State “general fund” appropriation for providing mental health services; and the primary funding source is MaineCare (i.e., Federal Medicaid funding, including so-called “Medicaid waiver funds” for children and adolescents); and
- Because Deaf and hard-of-hearing children have less resources available to them, their conditions both escalate and deteriorate more quickly than hearing children.

III. Data Collection

The Task Force heard presentations regarding the current system for identifying and tracking Deaf and hard-of-hearing children and adolescents.

Department of Education (DOE). **Christine Bartlett**, DOE Special Services Consultant, discussed special education data collected annually by DOE Child Development Services. Because current federal law requires students with disabilities to be categorized under a “primary disability”, DOE data mostly categorizes Deaf children with additional mental health conditions under “multiple disabilities.” Deaf children with additional disabilities can be captured under different data categories and there is currently no way to extract the total number of Deaf children with additional mental and behavioral health conditions from the different data categories (see white presentation handouts). Federal trends appear to be heading in the direction of collapsing data into fewer categories. DOE would need additional resources and staff to be able to fulfill new or expanded data collection and analysis requirements.

Newborn Hearing Screening Initiative. **Romy Spitz, Ph.D.**, Newborn Screening Advisory Committee Member and BDS Consultant, discussed the Newborn Hearing Screening Initiative and general issues affecting the identification and tracking of Deaf and hard-of-hearing children. The Newborn Hearing Screening Initiative identifies approximately 30-40 children each year with a hearing loss, of which 10% will be identified as Deaf. It is estimated that for every 7-10 years at least 3-4 children who are Deaf or hard-of-hearing with additional mental health conditions. The Newborn Screening Initiative is a grant-funded program within the Department of Human Services that will end in June 2005 and there is currently no follow up program until Deaf and hard-of-hearing children enter the school system. Ms. Spitz also noted the lack of a centralized service delivery system, coupled with labeling and definitional problems make it extremely difficult to identify and track this population (see e-mail message distributed at meeting).

Governor Baxter School for the Deaf (GBSD) Statewide Outreach and Consulting Services. **Karen Hopkins** discussed the role of the GBSD Early Childhood Intervention Services in identifying and tracking Deaf and hard-of-hearing children with emotional and behavioral health problems. GBSD continues to monitor and track children once they have been identified by the Newborn Screening Initiative and GBSD Early Childhood Intervention Services become involved. They reported that there are approximately 450 Deaf and hard-or-hearing children in Maine schools and that GBSD only has 3.5 full-time equivalent (FTE) consultants to provide services for this population. They expressed particular concern for the 180 adolescents enrolled in grades 7 through 12 who are not included in the DOE “child count” data, but who still are “at risk” children who are experiencing significant mental health issues and need intervention services.

Key points raised during Task Force discussion:

- The current identification system is fragmented across several agencies;
- Communication barriers and lack of capacity (too few providers with adequate training) may often result in misdiagnosis of children;
- Assessment and data collection are subject to multiple barriers for accurate reporting;
- There is a waiting list for children who need services through BDS “children’s services” programs;
- DOE special education data collection system (“child count”) doesn’t appear to take into account the Deaf or hard-of-hearing child with other mental health circumstances;
- DOE special education data collection system (“child count”) doesn’t include children that are not in public schools (e.g., who are home-schooled, enrolled in a private school or who are not enrolled in school);
- There is a lack of awareness among some Child Development Services system staff regarding the existing services and resources for Deaf and hard-of-hearing children with mental health needs;
- Regional sites of Child Development Services system operate under strong “local control” culture; and with two separate sets of state special education regulations, there is a disparity in how sites interpret their roles;

- Deaf children are sometimes categorized as “developmentally delayed” in DOE data, but their “developmental delays” persist because they are not getting adequate services.

IV. Proposals Designed to Improve Service Delivery

The Task Force heard presentations that examined ways to strengthen in-state specialty services and to foster collaborative efforts with other states.

Larry Taub, Superintendent, Governor Baxter School for the Deaf (GBSD), discussed ways to strengthen in-state services (see written testimony provided to Task Force). Superintendent Taub provided some background on discussion he held with GBSD staff, members of the Deaf community and therapeutic service providers about the need to conduct a feasibility study to establish a cost-effective, in-state program to meet the mental health needs of Deaf and hard-of-hearing children. He suggested that out-of-state placements are currently costing the state and others an average of \$200,000 per placement; and that we should explore partnerships with Community Counseling Center, Sweetser, Spurwink, etc. to examine the feasibility of providing appropriate services within the state. He indicated that when a child is placed out-of-state, we are still responsible for bringing them back and reintegrating them into their communities. He also suggested that Maine may be developing a “critical mass” of qualified therapeutic providers that could meet the specialized service needs of these children.

Dr. Stephen Green, Psychologist, discussed the limitations of current therapeutic treatment services for Deaf and hard-of-hearing children and the systemic changes needed to adequately meet the needs of this population. Dr. Green noted that current therapeutic treatment environments are based on hearing models, which isolate Deaf children and prevent direct access to treatment by preventing the development of direct relationships with providers and peers. Consequently, interpreters often become treatment providers, however they lack the appropriate mental health training. While there is the potential for interpreters to become an integral part of a clinical team, their role is prescribed by existing professional licensure and ethical standards and is therefore limited, to the roles defined by their particular certification.

Dr. Green suggested that systemic changes in policy, procedures and funding are necessary in order to adequately meet the needs of this population. He recommended the following four strategies to improve in-state specialized service delivery:

1. Utilization of “bridge people”: A “bridge person” facilitates communication between a child and their parents in the home and who provides language training. “Bridge people” can also help with implementing behavior management plans to assist families in becoming a therapeutic foster care family.
2. Development of comprehensive assessment teams: The emotional and behavioral health needs of Deaf children are often undiagnosed or misdiagnosed. The creation of assessment teams that can appropriately identify the comprehensive range of needs (i.e. neuropsychological, psychological, social, cognitive, emotional, behavioral, familial, linguistic, psychiatric, pediatric, linguistic, developmental, sensory, recreational) of Deaf children is vital to ensure proper treatment is secured.
3. Utilization of “wraparound” treatment foster care: “Wraparound” services involve the creation of a collaborative team of clinical providers that meet regularly and work toward a shared goal. The clinical team creates a “milieu without walls” which allows Deaf children to benefit from community-based treatment models
4. Utilization of distance technology: Distance technology can and should be utilized for assessment, intervention and monitoring cases in order to ensure equal access to qualified professionals.

Meryl Troop, BDS Director, Office of Deaf Services and Multicultural Diversity, discussed the need to improve the capacity of “signing” mental health providers. She noted the need to expand the capacity across the state of foster care workers, placement and respite providers who can “sign” and are capable of delivering culturally competent, linguistically accessible services. Ms. Troop also reiterated that the 1997 “request for proposal” (RFP)

model to create an in-state therapeutic treatment program for Deaf adolescents with serious emotional disturbances, based on the Western Pennsylvania School for the Deaf, was still a useful model for consideration.

Key points raised during Task Force discussion:

- Need to identify the number of Deaf and hard-of-hearing children served through the child protective service system, the treatment foster care system and the respite care system;
- State needs to invite officials from Sweetser, Spurwink and Youth Alternatives to engage them in addressing treatment programs and services for this population;
- Need to identify organizations and providers along the treatment continuum that are willing to develop treatment programs and models appropriate for Deaf children;
- Need to develop Deaf specialization tracks within current social service training programs (i.e. social work, psychology graduate programs);
- Need to focus on prevention and the development of comprehensive assessment teams to identify mental health issues at an early stage before they progress;
- Need to identify a lead agency responsible for the coordination and development of resources and services for Deaf and hard-of-hearing children; and
- Need to streamline current funding mechanism for out-of-state placements and develop a clear treatment path to ensure the successful reintegration of children returning from out of state placements.

V. Scoping Out Key Policy Issues and Developing a Work Plan -- Task Force Discussion

Task Force members discussed their perspectives on the purpose, key policy issues and expected outcomes of the study. The Task Force agreed on the following next steps:

- The Task Force agreed to hold its second meeting on Wednesday, December 17th from 8:00 a.m.-12:00 p.m. and its third meeting on Thursday, January 8th from 9:00 a.m.-1:00 p.m.;
- Staff will request a second extension of the Task Force reporting deadline from January 9th to January 23rd;
- Staff will request the appointment of Kirk Little, Director of Social Work Services, Spring Harbour Hospital in place of Jeannie Shacker (who is no longer employed by this hospital);
- Staff will gather written testimony from the Department of Corrections assessing the number of Deaf and hard-of-hearing children in custody and what access is provided to mental health services for these youth;
- Staff should review programs in other states (e.g., Pennsylvania, Florida, Connecticut, Massachusetts, and New York) to learn about the development of mental health services for Deaf and hard-of-hearing children;
- The Task Force agreed to invite the Commissioner of DHS and the Commissioner of BDS to participate in the second meeting; and to address issues, including but not limited to: (1) the extent to which there any foster care providers/caseworkers fluent in American Sign Language; and (2) the implications and impact of the BDS/DHS merger on service delivery for this population.

VIII. Adjournment

The Task Force meeting was adjourned at 2:00 pm.

Respectfully submitted,

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