Task Force to Study the Needs of Deaf & Hard-of-Hearing Children and Adolescents
December 17, 2003
Meeting Summary

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

Members absent: Sen. Betty Lou Mitchell

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

I. Introductions

Sen. Edmonds convened the Task Force meeting and asked Task Force members to introduce themselves. Following introductions, Task Force staff reviewed the meeting agenda and the November 20th meeting summary with the Task Force. Staff informed the Task Force that it received a second extension of its reporting deadline from January 9th to January 23rd.

The Task Force then engaged in a general discussion regarding ways to improve the delivery of in-state mental and behavioral health services for Deaf and hard-of-hearing children. The following points were made during the discussion:

- When talking about improving service delivery, there is a tendency to focus primarily on the needs of Deaf and "signing" children or more severely-involved children, but not on the needs of hard-of-hearing children;
- Mental health services for Deaf and hard-of-hearing children are not provided equitably across geographic regions of the state as services are concentrated in Region 1 and are unavailable in Region 3;
- Parents and professionals lack access to information about available resources and services;
- Current mental health services for Deaf and hard-of-hearing children focus on a "therapist-centered" treatment model; and given the lack of qualified in-state providers, we need to shift to more community-based treatment models (or "Chia");
- To appropriately address the mental and behavioral health needs of this population requires systemic and structural change; and although there are some open-minded providers with the capacity and flexibility to work with this population, it is not consistent within or across different organizations; and
- Need to improve the early identification and referral system to prevent the unnecessary onset of developmental delays and mental health conditions.

II. Designing a Culturally Competent and Linguistically Accessible System

Sabra Burdick, Acting Commissioner, Department of Behavioral and Developmental Services (BDS) and **Ron Taglienti**, BDS Children's System Manager, briefed the Task Force on current services provided by BDS to Deaf and hard-of-hearing children and adolescents. There are two entitlements under MaineCare for the provision of children's specialty services: (1) **in-home support services**, including day habilitation services for children with mental retardation, autism and mental health treatment needs; and (2) **children's behavioral health services**, which includes targeted case management. BDS serves 2000 children statewide, with approximately 37 children

waiting to receive in-home support services (down from 860 in February 2003). Children are required to receive services within 180 days after becoming MaineCare (or Medicaid) eligible and requesting services.

Mr. Taglienti informed the Task Force that BDS recently issued an e-mail survey to its staff (responses due by 12/23/03) to gather information on current service delivery. Specifically, the survey will assess demographic data, services provided, barriers in accessing services, qualifications of providers and experiences accessing interpreter services. In addition, Mr. Taglienti noted that BDS has been conducting "wraparound" training for the past two years to assist staff with the implementation of wraparound services in case management for children's services.

Main points raised during the discussion:

- Current MaineCare reimbursement rates for interpreters ($7 for ¼ hour) and lack of interpreter availability during evenings and weekends creates a barrier to accessible in-home treatment services for Deaf children and their families;
- Our focus should not be on securing more money for interpreters because the use of interpreters with hearing mental health providers is not a successful treatment model for Deaf children and adolescents;
- We need to look to other state models regarding ESL and other linguistic minority groups; however other spoken language groups have a "critical mass" that does not exist with the number and age ranges of Deaf and hard-of-hearing children and adolescents, (i.e., "resource- intensive" and (statistically) low incidence rates);
- While MaineCare changed its interpreter policy to provide full reimbursement for support services, it still does not adequately cover in-home treatment services;
- While Maine does have the ability to provide basic level mental health services to Deaf and hard-of-hearing children through its existing provider network, the State lacks intensive therapeutic services for children with more extensive needs;
- There is a lack of adequate in-home and respite care services available for Deaf and hard-of-hearing children and their families, especially for children in residential treatment who return home on weekends;
- Community-based prevention and intervention, including the "wrap around" treatment model, is the most innovative and effective approach to adequately address the mental and behavioral health needs of Deaf and hard-of-hearing children;
- The Governor Baxter School for the Deaf (GBSD) proposed budget cuts of $412,000 in FY 03-04 and $318,000 in FY 04-05 will greatly impact service delivery for these children;
- The main challenge with the national "wraparound" treatment model is its focus on case management; and case managers may not be clinicians, yet they are often placed in the position of making clinical decisions for teams;
- Medicaid rules currently require case managers to be graduate-level, licensed clinical social workers; and in Maine, in-home support workers and targeted case management workers must report to a licensed clinical social worker;
- The DHS/BDS restructuring commission is working to make case management a viable service that is consistent across departments and to also ensure optimum Medicaid funding;
- State priorities are often driven by litigation; and money spent on litigation diverts the focus and resources of state agency officials from serving the current needs of children and families;
- Interpreter-assisted treatment models are problematic because interpreters lack clinical training and are limited in their role by existing professional licensure and ethical standards; and the utilization of a "team" treatment approach with a coordinated, collaborative and mutually-accountable team of professionals can help overcome this limitation;
- Need to identify organizations and providers along the treatment continuum that are willing to develop and maintain treatment programs and models appropriate for Deaf children; and
- Need to institutionalize the cultural, social and emotional issues particular to deafness and also to include pre-service training in preparation programs for social service professionals.

III. Preliminary Findings, Conclusions and Recommendations

The Task Force identified four key problem areas for the development of preliminary findings and recommendations:

1. Improving capacity and delivery of culturally competent and linguistically accessible services

The Task Force noted that service delivery needs vary among geographic area, age, and level of care. Task Force members Stephen Greene, Jana Harbaugh and Jenn McCann agreed to form a subcommittee to develop potential findings and recommendations for the next Task Force meeting.

2. Identifying and tracking children in need of specialized services

The Task Force raised the following key points during discussion:

- Need to identify ways to maintain the Newborn Hearing Screening Initiative, which will lose funding in June 2005. While all hospitals have screening equipment, once the program ends new reporting and follow-up mechanisms need to be in place;
- Need to ensure that pediatricians are aware of all resources available to assist them with the identification, diagnosis and referral of children with audiological conditions;
- Maine needs to develop more resources for families and children once children have been identified as having audiological conditions;
- Early identification and improving parent and physician awareness is critical to prevent the unnecessary onset of developmental delays, which often cause subsequent mental health issues, (Note: Suzanne Chadwick will develop potential recommendations for next meeting);
- Maine needs a central data repository to identify and track this population; this would require outreach and education of BDS caseworkers, as well as Child Development Services System (CDS)and special education directors to help them in identifying and reporting information;
- University of Maine is currently developing the "Child Link" database to identify children ages 0-20 with a broad range of special health needs; and
- Need to train, physicians, clinicians and paraprofessionals to consider the needs of culturally diverse children.

3. Strengthening in-state specialty services and collaborative efforts with other states

The Task Force raised the following key points during discussion:

- Sweetser and the Governor Baxter School for the Deaf have discussed the possibility of day treatment program on Mackworth Island; and Sweetser is willing to explore ways to improve its capacity to serve this population, (Note: Rita LaBarbera will develop draft recommendations for the next meeting);
- Only 13 states have Deaf services positions within state mental health agencies; and most of these positions focus on adult mental health services and address other issues such as alcohol and substance abuse and diversity issues in addition to the needs of the Deaf population;
- The mental and behavioral health needs of Deaf and hard-of-hearing children fall into two main groups: (1) those children that need prevention, early intervention, and basic services; and (2) those children with severe mental and behavioral health needs; and
- These two groups have different service delivery needs and given Maine's limited capacity, those severe cases may be best served in out-of-state residential placements at this time.

4. Communication: Improving public awareness of available services and resources

The Task Force raised the following key points during discussion:

- Need to build upon existing resources (i.e. Division on Deafness Resource Book, BDS publications, etc.) and ensure information is distributed to parents, professional organizations, physicians and other clinicians;
- Need to improve web-based resources to ensure accessibility; while state agencies have more information on availability of services, the information is often buried within agency websites and is difficult to find;
- Need to develop a "single entry point" system to ensure parents can easily access information and services;
- BDS submits a report to the Legislature once every two years which can provide an opportunity to raise awareness of the mental health needs of Deaf and hard-of-hearing children; and
- State agencies need to build relationships with parent organizations around the state including Gaining Empowerment Allows Results (GEAR), Autism Society of Maine and the Maine Parents Association.

IV. Next Steps -- 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 third meeting on Thursday, January 8th from 8:00 a.m.-12:00 p.m. and its final meeting on Wednesday, January 14th from 12:00 p.m.-4:00 p.m.;
- The Task Force agreed to invite the Commissioner of DHS to participate in the third 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;
- The Task Force requested the following information from staff: 1) the number of Deaf and hard-of hearing children and foster care providers in the state child protection system, and 2) the number of Deaf and hard-of-hearing families within the child protection system that have lost of parental rights; and
- The Task Force members agreed to develop draft findings and recommendations before the next meeting and distribute them to the group via e-mail.

VIII. Adjournment

The Task Force meeting was adjourned at 11:00 am.

Respectfully submitted,

Nicole Dube, Legislative Analyst
Phillip McCarthy, Ed.D., Legislative Analyst