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Interdepartmental Coordination for Maine's Young Children with Disabilities

by Alan B. Cobo-Lewis



Alan B. Cobo-Lewis describes Maine's system of services for young children with disabilities. He notes that families of young children with disabilities face challenges in navigating Maine's service structure. There can be delays before children get appropriate evaluation, and there are sometimes problems with interagency referrals. Cobo-Lewis makes a number of recommendations regarding data linkage; coordination of eligibility determination from different funding streams; updating interagency agreements; and creation of a more efficient state departmental structure for services to children with disabilities. 🐉

INTRODUCTION

There is evidence that services provided early in life to children with a range of disabilities are effective (Guralnick 1997). Yet, states vary considerably in how services are actually provided (Hebbeler et al. 2007), and there is only limited knowledge on outcomes of this early intervention as actually practiced, as opposed to early intervention in model programs (Hebbeler et al. 2009). Families of young children with disabilities face significant challenges in navigating Maine's structure for services. Although Maine has attempted significant reform of its system for serving infants, toddlers, and preschoolers with disabilities in the past three years, delays and barriers still exist. Maine has been slow to address problems with interdepartmental coordination, including those that result in under-referrals. Maine must work to fix the aspects of the system that lead to underperformance while retaining those that have led to good performance. This article reviews patterns of good performance and underperformance and concludes with specific suggestions, especially on the need for greater interdepartmental coordination.

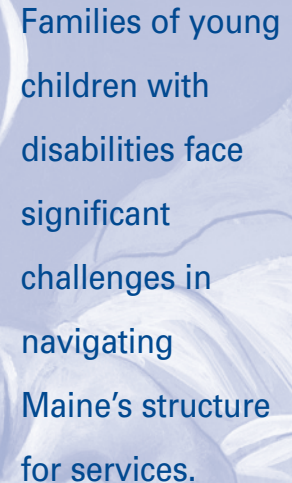
MAINE'S SYSTEM FOR SERVICES TO YOUNG CHILDREN WITH DISABILITIES

The Maine Department of Education (DOE) and the Department of Health and Human Services (DHHS) are the two primary state agencies that ensure the delivery of services for infants, toddlers, and preschoolers with disabilities. Some programs within these two departments pertain specifically to children with disabilities, and others serve a broader constituency. Child Development Services (CDS) in the DOE is responsible for early intervention for infants and toddlers with disabilities and for early childhood special education for preschoolers with disabilities. CDS is organized into regional sites that correspond roughly to Maine's 16 counties, plus a state CDS unit in the DOE for administration and general supervision. The DOE is also responsible for public pre-kindergarten programs.

The Office of Child and Family Services in the DHHS oversees child care, Head Start, child welfare (including adoption, foster care, and prevention of child abuse and neglect), home visiting (voluntary

parent education and family supports for first-time families with children prenatal through age five), and Children's Behavioral Health Services (CBHS; for children through age 20 who have developmental disabilities or delays, intellectual disabilities, pervasive developmental disorders or autism, and mental health issues). The Maine Centers for Disease Control and Prevention (Maine CDC) in the DHHS is responsible for, among other programs, the newborn bloodspot screening program, the newborn hearing program, and the birth defects surveillance program. The Office of Integrated Access and Support in the DHHS is responsible for determining eligibility for several programs, including Temporary Assistance for Needy Families (TANF), the food supplement program (formerly food stamps), and MaineCare (Maine's Medicaid system). In particular, a child can qualify for MaineCare either through low family income or through significant disability.

When a family suspects its child has a disability, it can face a cumbersome process for identifying the disability and qualifying for adequate services. The family can also face a cumbersome process even understanding what services are appropriate and available and how to navigate the system. The system is complex, with many entry points, different eligibility criteria for different programs, and different points of contact. There are caseworkers available to help—though there are even eligibility criteria for case management, and caseworkers may not always have a sufficiently broad perspective to help families with all their needs. In addition, there are nonprofit organizations and public instrumentalities of the state that can help families of children with disabilities. For example, under the federal Developmental Disabilities Assistance and Bill of Rights Act, each state has a systems change organization (Maine Developmental Disabilities Council), a protection and advocacy organization (Disability Rights Center of Maine), and a



Families of young children with disabilities face significant challenges in navigating Maine's structure for services.

What Is IDEA?

The federal Individuals with Disabilities Education Improvement Act (IDEA) defines early intervention and special education services for infants, toddlers, preschoolers, and school-age children:

1. Under Part C of IDEA states provide early intervention to infants and toddlers with disabilities. States may also choose to provide services to children at risk. (Maine does not.) Eligibility criteria can be broad, moderate, or narrow. (Maine's are narrow.) Part C federal funds are used for children with disabilities from birth through age two. States can also participate in a new "Part C option" that allows families to receive early intervention until they choose to enter the school system at a later age. (To date no state has taken the Part C option.)
2. Under Part B of IDEA states provide special education and related services to students with disabilities. Under Part B states must ensure that children receive "free appropriate public education."

Part B Section 611 federal funds are for special education from age three. Maine chooses to use Section 611 funds only for school-age children (age five to graduation or age 20, whichever comes first).

Part B Section 619 federal funds are for early childhood special education for preschoolers (age three to five). For preschoolers' education, special education includes participating in "appropriate activities."

university center for excellence in developmental disabilities (University of Maine Center for Community Inclusion and Disability Studies). There are also nonprofit organizations focusing on children's issues, legal issues, advocacy, and issues specific to particular disabilities.

INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT (IDEA)

The federal Individuals with Disabilities Education Improvement Act (IDEA) is administered by the U.S. Department of Education (U.S. DOE). IDEA provides for "early intervention" (Part C of IDEA, for infants and toddlers with disabilities) and "special education" (Part B of IDEA, for children with disabilities from age three). IDEA also provides for targeted funds and appropriate activities for preschoolers with disabilities (Section 619 of IDEA Part B). (See sidebar for a summary.)

Early intervention (Part C) is administered at the state level through state "lead agencies." Special education (Part B) is administered at the state level by state educational agencies. Part C of IDEA requires that a state have an interagency coordinating council for early intervention, and Part B of IDEA requires that a state have a state advisory panel for special education. In Maine, the Maine Advisory Council on the Education of Children with Disabilities (MACECD—pronounced "maist") serves as both the Part C interagency coordinating council and the Part B state advisory panel.

There are many models for ensuring the provision of services to infants, toddlers, and preschoolers with disabilities. According to the National Early Childhood Technical Assistance Center's Web site (www.nectac.org/partc/ptclead.asp), non-educational agencies serve as sole lead agency for early intervention in 38 states. In 10 states plus Washington, D.C., educational agencies serve as sole lead agency for early intervention. Some states have innovative collaborations. In Vermont and Nebraska, the Department of Education serves as co-lead agency for early intervention with a human services or health agency. Wyoming's Department of Health serves as lead agency for early intervention under Part C and also provides early childhood special education services to preschoolers with disabilities under Part B. This allows the Wyoming Department of Health to provide birth-to-five early intervention and early childhood special education services through a unique arrangement where the Wyoming Department of Education exercises general oversight over special education (Wyoming DOE 2007), but passes federal special education funds to the Department of Health

and ensures proper administration of the preschool special education program through an interagency agreement. In Pennsylvania, the Office of Child Development and Early Learning is jointly overseen by the Department of Public Welfare and the Department of Education (www.dpw.state.pa.us).

In Maine, the DOE serves as both the lead agency for early intervention (Part C) and the state educational agency for special education (Part B). Child Development Services in the DOE specializes in early intervention and early childhood special education for children with disabilities from birth until school entry (roughly birth to five years old).

DELAYS BEFORE APPROPRIATE EVALUATION

Systems Change Initiative for Pervasive Developmental Disorders

The Maine Developmental Disabilities Council is coordinating a systems change initiative to address the need for increased capacity and effectiveness in public services and supports for persons who have pervasive developmental disorders (PDDs, sometimes called the “autism spectrum”). While this article’s focus is broader than autism, some issues identified in the PDD systems change initiative pertain more broadly than just to autism. In particular, the systems change initiative sought to understand and make recommendations about shortening the wait for diagnosis and determination of eligibility. Only about half of children on the autism spectrum in Maine are diagnosed before kindergarten (Maine DHHS 2007) even though there is evidence that autism can be diagnosed at least as young as 18 months. Thus, children in Maine who have autism are not being diagnosed early enough to receive the full benefit of early intervention (Maine DHHS 2009).

Families in the PDD systems change initiative identified several points in their history where time was wasted in getting their children appropriately evaluated and diagnosed. These included discounting of legitimate parental concerns by pediatricians in well child visits, delays of months before a CDS team referred to an appropriate assessment, and months spent on waiting lists between referrals and the performance of

an evaluation. Participants in the PDD systems change initiative made 26 specific recommendations (Cronin 2008). Among them were recommendations about how to develop a standardized screening and referral process and how to ensure delivery of evaluation results in a timely manner. Participants recommended that the Maine DOE and the DHHS convene a joint workgroup for appropriately broad approaches for diagnosis and treatment, braiding funding streams, rationalizing case management to improve coordination, designating a single point of contact during the screening/evaluation process, and creating an integrated system centered on the child’s needs from initial concern through evaluation. Participants also made specific recommendations on standardization of assessment, tracking, and evaluations and assessments, and on materials explaining the process to families. Most of these recommendations would pertain just as much to improving Maine’s approach to families of children with other disabilities.

Compliance with IDEA Timelines

IDEA requires that no more than 45 days elapse from referral to CDS of an infant or toddler for early intervention to completion of evaluation and initial assessment and meeting of the family’s individualized family service plan (IFSP) team to determine eligibility and write a service plan if the child is determined eligible (Code of Federal Regulations, Title 34 Sections 303.321(e)(2), 303.322(e)(1), July 1, 2008). Nationally, however, only about 60 percent of children get an IFSP within 45 days of referral (Hebbeler et al. 2007). Although Maine falls short of the requirement for 100 percent compliance, it has reported to U.S. DOE that compliance in recent years has been more than 90 percent (Knudsen 2008; Maine DOE 2009). However, the DOE has instituted detailed on-site monitoring visits at the 16 regional CDS sites, and on-site reviews of individual children’s files suggest a median compliance rate of 75 percent (www.maine.gov/education/speced/cds/monitoring/index.html). The statewide figure of 90 percent derives from computerized records of all children referred to early intervention (roughly 1,600 children per year), whereas the site-specific data of 75 percent derive from chart review (intensive review of at least 10 percent of charts at each site). This discrepancy suggests that on-site monitoring

Subcommittee to Study Early Childhood Special Education

The subcommittee had a diverse membership of 28 stakeholders, including disability advocates (an adult with a disability and four parents of children with disabilities), CDS members (two contracted service providers, two service providers employed directly by a CDS site, a regional board member, and a regional site director), a Head Start program director, a child care program director, public school members (a pre-kindergarten teacher, an elementary school principal, two special education directors, a superintendent, and a school board member), a delegate from MACECD, four legislators, two delegates from DOE, and two delegates from the DHHS.

and technical assistance may be a valuable training opportunity for CDS site staff, and that it would help improve the validity of Maine's data collection system. (In addition to being good policy, ensuring the validity of data is a requirement of IDEA.) The on-site monitoring data are consistent with the concern expressed in the PDD systems change initiative about delays before diagnosis and appropriate evaluation. However, examining specific family stories in the PDD systems change initiative indicates that some children were given an initial evaluation in a timely fashion, but experienced substantial delays before obtaining an appropriate evaluation. This suggests that CDS and CBHS should give attention to ensuring that all referred children be evaluated comprehensively enough to determine what services would meet their needs.

SUBCOMMITTEE TO STUDY EARLY CHILDHOOD SPECIAL EDUCATION

In 2006 Maine created the Subcommittee to Study Early Childhood Special Education to make recommendations about early intervention and early childhood special education. The subcommittee was authorized to introduce a bill to implement its recommendations. (See sidebar for information on the membership of the subcommittee.) The subcommittee was co-chaired by a parent (myself) and a CDS contracted service provider and produced eight findings and 21 recommendations. The 123rd Legislature

passed a series of three bills to implement 17 of the subcommittee's 21 recommendations: Public Law 2007 chapter 450, Public Law 2007 chapter 307, and Public Law 2007 chapter 530. The major themes of these recommendations were (1) to build on the good aspects of Maine's existing structure for birth-to-five services, (2) to increase interagency collaboration among the DOE, the DHHS, public schools, and other community resources, and (3) to increase accountability of system components (Subcommittee to Study Early Childhood Special Education 2007).

MAINE'S EARLY IDENTIFICATION IS SLIPPING

IDEA requires that states have a system for identifying children with disabilities. This is called "child find." The subcommittee examined Maine's performance at early identification and for the most part, found success. Where the subcommittee found Maine to have fallen short, it recommended specific actions to address it. Unfortunately, in the years that have followed, Maine has slipped on a key area of early identification, and where it needed to improve in early identification, action has been slow, and the state has not yet shown improvement. Recent actions, however, suggest that improvement is within reach if interdepartmental issues can be resolved.

"Mind the Gap": Identification of Preschoolers with Disabilities

The subcommittee considered a proposal from the DOE to move early childhood special education for preschoolers to the K-12 public school system. One reason was that since education through at least part of K-12 is essentially universal, it could improve Maine's success at identifying preschool children with disabilities. The data, however, did not bear out that hypothesis. As it turns out, Maine's CDS system is quite successful at identifying preschoolers with disabilities, thus fulfilling the federal mandate for child find, at least for preschoolers.

Figure 1 shows Maine's special education rate for preschoolers (three- to five-year-olds) and older children (six- to 17-year-olds) from 2004 through 2007, along with data from the other states and District of Columbia. Maine's identification rate is high in both

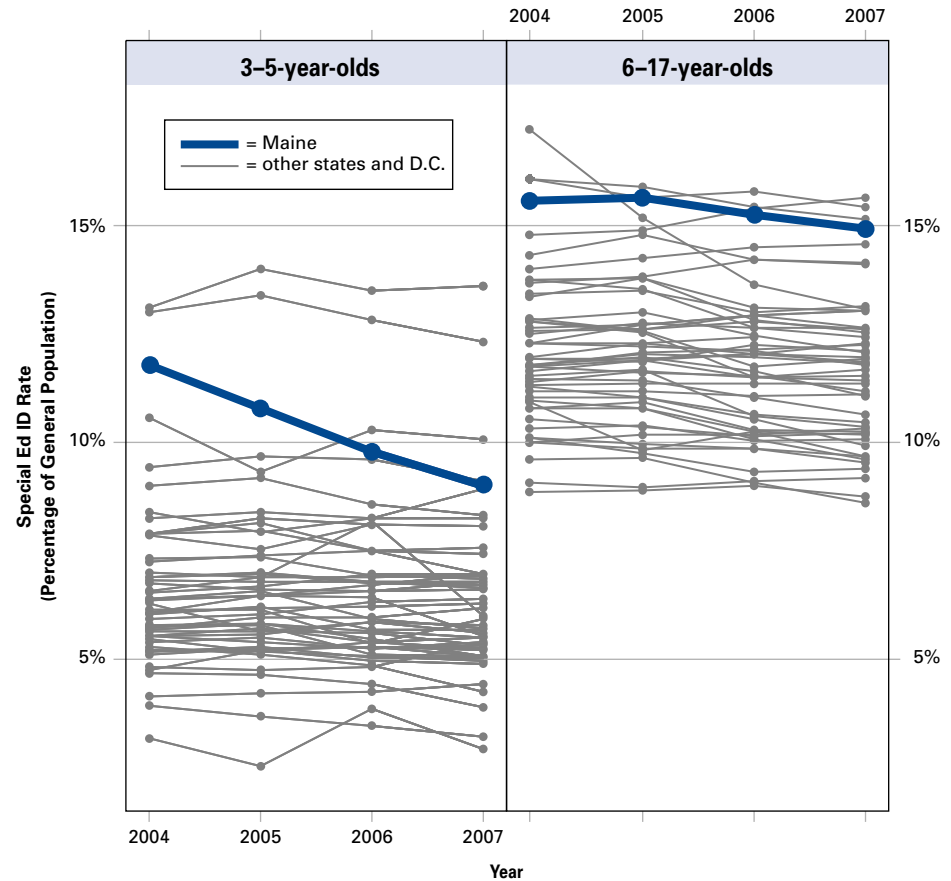
FIGURE 1: IDEA Part B: State-by-State Trends in Special Education Identification Rates for Preschoolers and School-age Children

categories (the blue lines for Maine are above most of the gray lines for the other states). Maine's identification has fallen in both categories, but while it has fallen only slightly for six- to 17-year-olds, it has fallen dramatically for three- to five-year-olds.

What does this mean for success at early identification? With all the variation between states and across time in special education identification in each age group, how can we assess success at early identification? Because states differ on special education rates, to fairly compare states on success of preschool identification, one should examine the ratio of identification rates among three- to five-year-olds to identification rates among six- to 17-year-olds. Whatever a specific state's baseline rate of children in special education, this ratio would be close to 100 percent (no gap between preschoolers and older students) for states that are successful at early identification and much less than 100 percent (large gap between preschoolers and older students) for states that are less successful at early identification. Data examined by the subcommittee (the 2004 data in Figure 1) indicated that under the CDS system at the time, Maine's ratio was better than more than 90 percent of states. Unfortunately in the years since, Maine has slipped. Although Maine outscored 92 percent of other states and Washington, D.C., in 2004 (ratio of 76 percent), the ratio has slipped steadily since then. In 2007 Maine outscored only 82 percent of other states and Washington, D.C. (ratio of 60 percent). Thus, Maine's gap between preschool identification and school-age identification is growing.¹

Identification of Infants and Toddlers with Disabilities

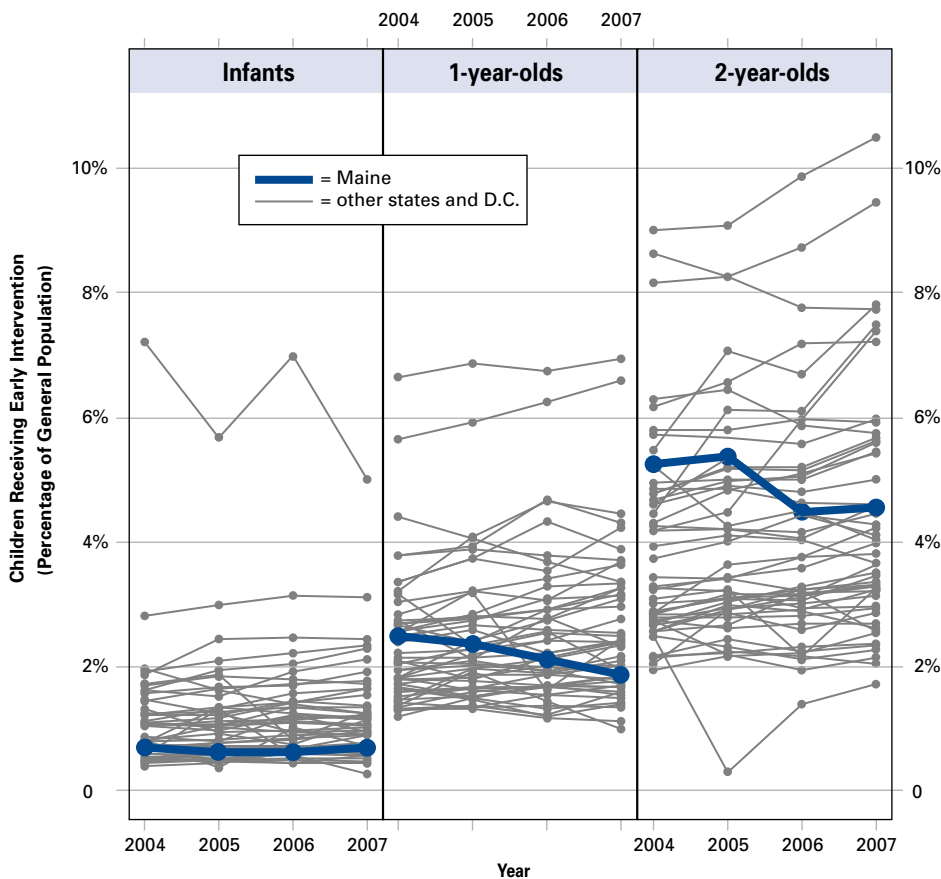
The U.S. DOE has highlighted very early identification as a priority: it requires every state to report on success at identifying infants (children under age one) needing early intervention and to report on success at



Source: All data are from www.ideadata.org

identifying infants and toddlers overall (children under age three). The subcommittee noted that Maine was close to the middle compared to other states in identifying birth to two-year-olds who need early intervention. Figure 2 (page 74) shows Maine's early identification rate for infants, one-year-old toddlers, and two-year-old toddlers from 2004 through 2007, along with data from the other states and Washington, D.C. As the middle and right panels of Figure 2 indicate, Maine has slipped in identifying toddlers. Considering birth to two-year-olds overall, Maine has slipped from ranking better than 68 percent of states in 2004 to ranking near the median in 2007, though in 2007 Maine did still identify a higher proportion of

FIGURE 2: IDEA Part C: State-by-State Trends in Early Intervention Identification Rates



Source: Early intervention data from ideadata.org; population from U.S. Census

birth to two-year-olds than 80 percent of the 15 other states with narrow eligibility criteria (www.ideainfanttoddler.org/pdf/2007_Child_Count_Data_Charts.pdf).² This may have reflected a state effort to reduce identification rates: the Maine DOE's most recent annual submission of these data to the U.S. DOE notes that "the original targets were set anticipating efforts to reduce the number of children identified so that Maine's percent of children identified would be more closely aligned with the overall percent of children identified for the 50 states and D.C. and more importantly within the ability of the state's economic climate to adequately serve the children identified" (Maine DOE 2009: 38). But child find is

not discretionary—the U.S. DOE responded by reminding Maine of the state's obligation to identify all eligible children (Maine DOE 2009).

In spite of Maine's success at identifying preschoolers with disabilities and its mid-range performance at identifying toddlers with disabilities, the subcommittee found that Maine did not do well at identifying infants. The left panel of Figure 2 shows the percentage of infants in each state receiving early identification. In 2004 Maine outscored only 30 percent of other states and Washington, D.C., identifying only 0.69 percent of infants for early intervention. This was well below the median and Maine's long-range federal target, which was near one percent. By 2007 Maine's performance on this federal benchmark had barely budged, with Maine outscoring 26 percent of other states and Washington, D.C., identifying only 0.71 percent of infants for early intervention and falling short of the 0.85 percent that Maine had identified as its target for that year (Maine DOE 2009).

Maine's performance on infant identification has consistently fallen well short of targets and national norms. The Maine DOE has indicated to the U.S. DOE that "the state does not expect large increases" and has requested that its short-term targets for identifying infants be recalibrated downward (Maine DOE 2009: 35). This would not solve the problem.

INTERDEPARTMENTAL REFERRALS

Referrals from Health and Human Services to Education

Under federal law, infants and toddlers can be eligible for early intervention either because they are experiencing developmental delays or because they have a diagnosed physical or mental condition with a high probability of resulting in such a delay. The identification

process is different for children with delays versus those with diagnosed conditions; children with a diagnosed condition can typically be identified younger—potentially at birth (Hebbeler et al. 2007). The anomalously low identification of infants with disabilities in CDS may be related to the referral process for young children who may already have diagnosed conditions. The state's first contact with infants with disabilities is often not through CDS, but through the DHHS. For example, the Maine CDC operates the newborn hearing program (for universal screening of newborns for hearing loss and follow-up when necessary), the newborn bloodspot program (for universal laboratory testing of infant blood samples for metabolic or genetic abnormalities that can result in disability), and the birth defects surveillance program (for identification and investigation of birth defects in children and to maintain a central registry of cases of birth defects). Referral of children from Maine CDC to CDS is neither universal nor automatic. This lack of consistent referrals from Maine CDC to CDS may be in large part responsible for Maine's low identification rate of infants who need early intervention. Better referral from Maine CDC to CDS could move Maine's early intervention identification for infants from the bottom third to at least the median or even the top third of states (Cobo-Lewis and Hatch 2007).

Based largely on this information, the subcommittee made a specific recommendation for the state to mandate referrals to CDS from these three programs in Maine CDC. This recommendation was ultimately incorporated into state law. To facilitate these mandated referrals, and to address a host of other interagency issues, the subcommittee also made a recommendation that the DOE and DHHS update their "interagency agreement," which had not been updated for more than a decade. Although the DOE and the DHHS have agreed upon an outline and have drafted some sections, the updated agreement has not yet been executed at the time of this writing (September 2009). In testimony to the Joint Standing Committee on Education and Cultural Affairs on March 23, 2009, however, the departments indicated that their intention is to update the interagency agreement by October 2009.

In its annual report to U.S. DOE, the Maine DOE cited 19 accomplishments in "improvement

activities" for identifying infants with disabilities (Maine DOE 2009). Some addressed the subcommittee's recommendation to update the interagency agreement to ensure that children are referred from Maine CDC to CDS, but in my opinion, most of these improvement activities do little to address the fundamental requirement for these interagency referrals. Recently, however, Maine CDC and CDS have established a process for centralized referrals to CDS from the Maine CDC's newborn hearing program (Stockford and Hannigan 2009). Processes have not yet been established for referrals to CDS from the Maine CDC's newborn bloodspot program or the birth defects surveillance program. It is important for the departments to establish those processes, however, and also to report data on the success of the processes for referral to CDS from all three of these programs in Maine CDC.

Referrals from Education to Health and Human Services

The Maine DHHS is not just a potential referral source for CDS; it also ensures provision of some services. About half the children served by CDS are eligible for MaineCare, either based on low family income or on their disability. While the eligibility criteria for Children's Behavioral Services (CBHS) in the DHHS are different from eligibility criteria in CDS, there is substantial overlap in children served by the two programs. Some services in CBHS (such as respite care) do not require a child to have MaineCare, but most services in the program do require the child to have MaineCare.

With family consent, CDS is able to bill MaineCare for many services it provides to enrolled children. Because about two-thirds of MaineCare expenditures are paid with federal funds, this is highly cost-effective for the state. In accessing MaineCare, however, CDS must abide by the regulations governing it. For example, federal Medicaid regulations require that persons receiving services have a choice of service provider. This has the potential to contrast with typical CDS practice. CDS may consult with the family about providers, but the choice of provider can be at the discretion of CDS, subject to the family's right to challenge a decision in dispute resolution procedures.

More generally, when a child is deemed eligible for CDS services, there is sometimes disagreement between CDS and the family over the intensity or nature of the service. CDS is required by IDEA to ensure that preschoolers with disabilities receive a “free appropriate public education,” but children sometimes need services that go beyond what CDS considers a free appropriate public education. One example might be that a family or other members of the child’s team might conclude that a child needs services during the summer that could be considered part of free appropriate public education, but CDS can interpret the DOE rules as imposing a more stringent requirement before agreeing to provide services beyond the school year. Alternatively, CDS may agree to the provision of summer services at a reduced frequency or intensity.

Maine should consider administrative coordination—and even an administrative merger—of CDS [Child Development Services] and CBHS [Children’s Behavioral Health Services] to simplify the process for families and to avoid administrative duplication.

Under federal Medicaid regulations, children covered by MaineCare must receive services that are medically necessary, including medically necessary services to treat or ameliorate a child’s physical and mental health condition. Under state rules, CDS has typically been the gatekeeper for some MaineCare services (notably developmental therapy). As an educational agency operating under IDEA, CDS has understandably applied an eligibility criterion of free appropriate public education rather than applying a medically necessary criterion. This conflict between Medicaid’s medically necessary criterion and IDEA’s free appropriate public education criterion triggered

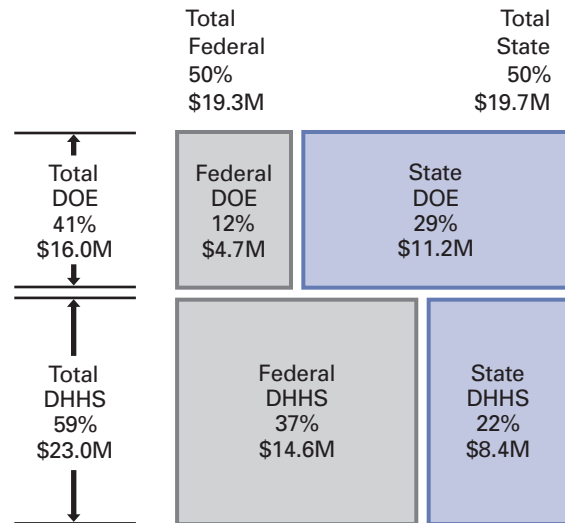
a lawsuit in federal court against DHHS (*K.S. v. Harvey*) to require the DHHS to ensure provision of medically necessary services to children in CDS who are covered by MaineCare. The lawsuit was settled in fall 2008, and the terms of the settlement require CDS to give notice to families of MaineCare-eligible children in CDS of the processes for seeking approval for services, including services that may go beyond what is provided in the child’s individualized CDS plan. This means that families in MaineCare can choose to access CBHS for services denied by CDS. In addition, state law since 2007 has required that CDS make appropriate referrals to public and private resources, regardless of a child’s eligibility for CDS services.

Although the settlement agreement was important to ensure that Maine comply with federal Medicaid regulations, it means that there is now additional duplication of process between CBHS and CDS. Maine should consider administrative coordination—and even an administrative merger—of CDS and CBHS to simplify the process for families and to avoid administrative duplication. A coordinated or merged unit could assess the child’s needs and braid funding to meet those needs. A model worth looking at is Wyoming’s, noted earlier, where the state education department monitors early childhood special education, but essentially subcontracts its coordination to a unit of the state health department.

DATA LINKAGE

Another consequence of services for children with disabilities being spread between the DOE and the DHHS is data fragmentation. To make good policy decisions, it can be helpful to be able to link individual-level records between state agencies. This can be done in a way that keeps individual-level data anonymous to protect privacy. Such linkage can address important issues such as how effective is early intervention as measured by outcomes years later in school, or how many children are receiving services from both departments and what are their eligibility categories in each data system. These questions are important in monitoring disabilities; for example, to determine autism prevalence, it is important to count persons with autism identified in the health system and in the

FIGURE 3: How the Funding Pieces Fit Together: “Mosaic Plot” Showing Rough Breakdown of Major Funding Sources in Child Development Services



Note: Area of each of the mosaic’s four cells reflects the contribution of corresponding funding stream. Data derive from analysis of commissioner of education’s testimony on proposed FY 2007 CDS budget (Maine DOE 2005) and FY 2007 Federal Medical Assistance Percentage (U.S. DHHS 2005). DHHS total is based on commissioner of education’s estimate of \$23 million in total MaineCare charges for CDS, and calculations of state and federal share are based on published Federal Medical Assistance Percentage of 63.27 percent. DOE detail is based on commissioner’s estimates of \$2,194,384 in early intervention IDEA funds, \$2,553,622 in preschool IDEA funds, and \$11,235,307 in requested state appropriation to CDS.

The state appropriates money from the general fund to the DOE, and the federal government awards money to the state DOE under Part C of IDEA for early intervention services (infants and toddlers) and Part B Section 619 of IDEA for early childhood special education (preschoolers). (The federal government also awards money under Part B Section 611 of IDEA for special education for children age three to 20, but the Maine DOE uses its discretion to allocate all of the Section 611 money to K-12 special education.) In addition, under Part C of IDEA, some money is recoverable from “family cost participation” (the term in IDEA that includes family fees and private insurance), but this is not a major source of funding in Maine, so is not included in Figure 3.

education system, but not to double-count those identified in both systems. Data linkage is also necessary to address specific policy questions about referrals from Maine CDC to CDS. For example, what proportion of children in the Maine CDC programs were in CDS before referrals were required by state law, and at what ages did these children enter the CDS system?

“Protected health information,” such as is often found in the data systems of the DHHS, is governed by privacy provisions issued under the federal Health Insurance Portability and Accountability Act (HIPAA) (www.hhs.gov/ocr/privacy). Educational records, as often found in the data systems of the DOE, are governed by the privacy provisions of the federal Family Educational Rights and Privacy Act (FERPA) (www.ed.gov/policy/gen/guid/fpco/ferpa). In exercising caution about compliance with HIPAA and FERPA, state agencies can be reluctant to share data even when there are protocols for sharing that are compliant with both HIPAA and FERPA. This issue was studied by the Maine Education Policy Research Institute and the completed report (Mason 2008) outlines methods for encrypted data linkage that have been implemented by Maine researchers working with sensitive health, education, and juvenile justice data in other states. Maine needs to take advantage of these encrypted linkage methodologies to address inter-agency data issues.

Reidt-Parker (this issue) has further discussion of the importance of data linkage, pointing out that quantifiable and credible benchmarks are essential for evaluating the quality, affordability, accessibility, and outcomes of Maine’s early childhood systems more generally, not just in the area of children with disabilities. She also notes that “comprehensive data to establish and monitor these benchmarks are not readily available, even though a substantial amount of information is being collected within and across the departments of state government” (Reidt-Parker this issue: 31)

FUNDING

The major funding sources for CDS reflect the need for interdepartmental coordination. Figure 3 summarizes how the major funding pieces for CDS fit together.

Many states use Medicaid to help to fund services such as CDS. In Maine, the federal government matches state MaineCare dollars on roughly a 2:1 basis under the Federal Medical Assistance Percentage, so services that CDS is able to bill MaineCare leverage substantial federal funds. The figure clearly shows that CDS is funded roughly half by the federal government and half by state government. It also shows that almost 60 percent of state and federal funding for CDS passes through the DHHS, even though CDS is located in the DOE. This requires substantial coordination between the departments to ensure that both departments comply with all relevant regulations.

Although the DOE has found savings in administrative reorganization, the pressure on the system that delivers services to children with disabilities is obvious.

The 2007 budget for CDS represented a cut of roughly one-third in state appropriation to the DOE, amounting to roughly 16 percent of CDS's total budget (Maine DOE 2005). Since then the state appropriation to CDS has been flat-funded. According to the legislature's Office of Fiscal Program Review, educating a child with a disability in CDS is, on average, less expensive to the state than educating a child with a disability in the K-12 public school system (www.mainelegislature.org/legis/bills/bills_123rd/fiscal/notes/FN031702.htm). Although the DOE has found savings in administrative reorganization, the pressure on the system that delivers services to children with disabilities is obvious. This is reflected in the Maine DOE's annual filings with the U.S. DOE, which cite economic challenges and budgetary constraints in explaining Maine's performance at identifying infants and toddlers with disabilities (Maine DOE 2009).

The American Recovery and Reinvestment Act of 2009 (the "stimulus package") has ameliorated the fiscal situation by delivering an additional \$2.1 million in IDEA early intervention funds and an additional

\$2.6 million in preschool Part B Section 619 IDEA funds (www.maine.gov/education/recovery/), and also by temporarily raising the Federal Medical Assistance Percentage to 73.37 percent as of the time of this writing (www.maine.gov/dhhs/recovery/projects/oms-fmap.shtml). If the additional federal IDEA money for infants, toddlers, and preschoolers is spent over two years and is spent entirely on CDS, then the net effect of the stimulus package might be up to roughly a six percent temporary increment to the annual CDS budget. But even such an influx would not raise the total CDS annual budget to its 2005 level. In addition, stimulus package money is one-time, and the intention is to make wise investments that emphasize reform and minimize a "funding cliff" (U.S. DOE 2009), not to plug holes in existing budgets. An example of a good use of stimulus package money would be to create a referral system to CDS from Maine CDC's newborn bloodspot and birth defects programs (Debra Hannigan personal communication, June 1, 2009).

Part C of IDEA allows family fees for early intervention, including a sliding fee scale, for some early intervention services. Within the past five years, Connecticut instituted a sliding fee scale that is substantially more aggressive than Maine's. In fiscal year 2008, Connecticut netted \$697,744 from its sliding fees (Connecticut Birth to Three System 2008). Scaled down to Maine's lower early intervention enrollment and taking into account Maine's lower median income, family fees would yield only modest income.

One feature of a sliding fee scale is that it can be structured to give families with private insurance an incentive to allow CDS to access their private health insurance. Connecticut halves the fees if families consent to the use of private health insurance to help fund early intervention services (www.birth23.org/family%20participation%20adjustment%20letter.pdf), and Maine eliminates fees with consent to access insurance (Debra Hannigan personal communication, August 5, 2009). Thus, while sliding fees yield only modest amounts, they may be helpful at raising money from private insurance. In Connecticut, private insurance contributed \$3.4 million to early intervention in fiscal year 2008 (Connecticut Birth to Three System 2008). Since 71.4 percent of children in Connecticut are

covered by private health insurance, versus 51.9 percent in Maine (Cohen and Makuc 2008), a realistic estimate for Maine would be \$592,955 (1.5 percent of the total estimated CDS birth-five budget in Figure 3, page 77), less whatever funds Maine is currently recovering from private health insurance for early intervention.

The Maine legislature is currently considering a requirement that private insurance cover early intervention for birth to two-year-olds up to an annual cap, along with covering autism treatment for persons under age 21 up to a cap. Bills in the 124th Legislature to address these possibilities (LD 425 and LD 1198, respectively) have been referred to the state Bureau of Insurance for assessment of their effects on health insurance premiums.

CONCLUSION AND RECOMMENDATIONS

CDS is more cost-effective than K-12 public schools, but interdepartmental issues continue to hamper Maine's ability to address issues of early identification, service coordination, and data analysis. And funding remains an ongoing concern. Following are specific recommendations to address these issues:

- **Data linkage.** Improved data linkage among departments would help to address questions about how resources are allocated and how effective programming is. Maine should take advantage of encrypted linkage methodologies.
- **Interagency referrals.** As required by law but not yet fully implemented, the Maine DHHS and the Maine DOE must automatically refer children as appropriate to CDS from Maine CDC's surveillance programs. Intervention for children with disabilities should begin as early as possible.
- **Coordinate eligibility determination from different funding streams.** Under the settlement agreement in *K.S. v. Harvey*, Children's Behavioral Services is determining eligibility for medically necessary services for MaineCare-eligible children birth to age five. This process was necessary to ensure compliance with Medicaid regulations, but it does mean that there is duplication of effort between CBHS

and CDS. Maine should consider a streamlined system where CBHS and CDS could work together so that families could find out in "one-stop shopping" what services their child is eligible for. Children birth to age five should be able to get a unified individualized service plan that includes all services and that coordinates the determination of which funding stream to tap for each service.

- **Update the interagency agreement.** The existing interagency agreement is outdated. To achieve all the goals above, Maine should finally execute a detailed interagency agreement to clearly define roles and responsibilities.
- **Birth to age five services.** Given Maine's good identification of preschoolers with disabilities, especially compared with states that serve preschoolers with disabilities in the K-12 system, Maine should continue operating a birth to age five system for early intervention and early childhood special education.
- **Consider a more efficient structure.** Given the slow implementation of needed interagency policies between Maine CDC and CDS, and given the duplication of effort between CBHS and CDS, Maine should consider a more aggressive approach to streamlining services between the two major departments. A model such as Pennsylvania's would create an office of child development and early learning to coordinate activities between departments. A model such as Wyoming's would reduce duplication of effort by consolidating CDS and CBHS.
- **Early intervention insurance mandate.** A more aggressive family fee structure for early intervention would yield modest revenue by itself, but coupling Maine's existing family fee structure that with a requirement for private health insurance to cover a portion of early intervention could yield revenue of around 1.5 percent of the total CDS budget—more if an insurance mandate included developmental therapy. 🦋

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ENDNOTES

1. An anonymous reviewer of this article asked to what extent the drop in three- to five-year-old identification might be attributed to ongoing attempts by the state to impose better uniformity across the regional CDS sites via statewide assessment procedures. There is indeed variability among the regional CDS sites in identification, but CDS variability in special education identification is roughly the same as variability among K-12 school districts when measured on a relative scale, though CDS is actually less variable on an absolute scale (Meterer et al. 2006). Analysis by the author of site-by-site changes in CDS identification since 2004 have so far not revealed any obvious correlation between overall identification rate and changes in variability.
2. An anonymous reviewer correctly noted that under Part C of IDEA some jurisdictions (about one-eighth of states and territories) serve infants and toddlers at risk along with serving infants and toddlers with disabilities. If jurisdictions that also serve infants and toddlers at risk are excluded from the analysis then the 2007 figures in this paragraph barely change (Maine still ranks near the median among states and territories that do not serve infants and toddlers at risk, and Maine still ranks higher than 80 percent of such states and territories with narrow eligibility criteria.)

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