

New Jersey's Early Intervention Program:

The Need for Fiscal Reform and Long Term Financing



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Introduction

Numerous studies indicate that the provision of early intervention services to children born with developmental delays and disabilities is critical in ameliorating deficits.¹ The timely provision of such services can reduce the need to use special education services, developmental disabilities programs, and other state programs as the child ages and result in tremendous savings to the state in the future. The New Jersey Legislature acknowledged in the early intervention authorizing statute that “it is in the best interest of the State to provide a comprehensive system of early intervention services to support infants and toddlers with disabilities and their families.”² Unfortunately, many children and their families fall through the cracks or are poorly serviced, if at all. While federal law guarantees a right to early intervention services, the availability of these services may still be out of reach because of inadequate funding for the program and the family cost share system.

Part C of the Individuals with Disabilities Education Act (IDEA)³ is the federal law that governs the provision of services to infants and toddlers from birth to age three and their families. Under Part C, states define developmental delay; thereby creating eligibility criteria for the program and often defining, and limiting the availability of services.⁴ In New Jersey, developmental delay is defined as a 33% delay in one area of functioning or a 25% delay in two or more.⁵ New Jersey’s criteria places it among the moderate definition states, which means that some states have a more liberal definition of developmental delay and others have a more restrictive definition. Because the federal government provides only limited funding to carry out the program, the states are left to devise a funding structure to sustain the program. The IDEA allows states to develop a system whereby families may be required to bear a share of the cost for services, a burden that may limit access to services.⁶ This reflects Congress’s intent that the program be funded through a variety of federal, state, and private funding sources. Other options for funding through Medicaid and mandatory insurance coverage also may be used, if a state wishes to pursue these sources.

Disability Rights New Jersey (formerly known as New Jersey Protection & Advocacy, Inc.), the designated protection and advocacy system for people with disabilities in New Jersey, believes there is reason to be concerned about the financial security of the State’s early intervention system. Funding prospects for New Jersey’s 2009 fiscal year appear bleak. Departments are being asked to cut budgets by 20%. As the financial costs of the early intervention system continue to grow through increased services and increased enrollment, the State continues to look to families to bear a higher burden of costs without looking to other options such as a Medicaid waiver, increased use of Medicaid EPSDT services, and mandatory insurance coverage of early intervention services. New Jersey will be unable to maintain a quality early intervention system if it continues to look to families to bear the burden of increasing costs. The State is creating a system that discourages family participation and is punitive in nature. The State of New Jersey must develop a long-term financing plan for the early intervention system to ensure that quality services are provided and that no family is discouraged from participating in a critically important program.

Background

1. Children with Developmental Delays in New Jersey

At any point during the year, there are more than 9,000 families in New Jersey who have children with developmental delays participating in the early intervention system.⁷ The State indicates that more than 17,400 families participated in the early intervention system during the State's 2006 fiscal year.⁸ These children have a wide range of delays and disabilities such as hearing impairments, speech delays, and diagnoses of cerebral palsy or autism. While the services will vary depending upon the needs of the child and family, all families within the program are entitled to an individualized program that assists families in meeting the developmental needs of their infants and toddlers with developmental delays.

The annual December 1 count is a point in time count that is reported to the U.S. Department of Education. The numbers of families participating in the early intervention system have increased from 7,790 to 9,310 based upon the December 1 counts from December 2004 through December 2006.⁹ The New Jersey Department of Health and Senior Services acknowledges that in the past the data collection was inaccurate, but has indicated that it is too cumbersome to correct the December 1 counts with the federal government. Therefore, the actual number of families participating in the program may not be known. The federal government bases its funding to states on the ratio of infants and toddlers within a state to the number of infants and toddlers throughout the country.¹⁰ While New Jersey continues to increase the number of infants and toddlers identified and served, the ratio of total number of infants and toddlers within New Jersey to the number of infants and toddlers throughout the country has decreased, thereby decreasing New Jersey's federal funding.

Based upon the December 1 count, New Jersey ranks below the national average in identifying eligible children between birth and age one. New Jersey identifies and serves 0.56 percent of all infants between birth and age one and the national average is 0.99 percent.¹¹ The average for states with eligibility criteria similar to New Jersey's criteria is 0.90 percent.¹² The State is looking to increase the identification in this population because the U.S. Department of Education cited this as an area in need of improvement for New Jersey. A suggestion from the State Interagency Coordinating Council is to remove the corrected age on premature infants and toddlers when determining eligibility for early intervention services.¹³ Currently, premature infants and toddlers ages are adjusted until two years of age. Therefore, if the infant is born two months earlier, the birth age may be nine months but the adjusted age of development is seven months. By removing the corrected age for premature infants and toddlers, substantially more families may be eligible for services and enter the system.

However, the number of participating families is only one aspect of the cost to the system. There are the additional costs in the evaluation process for those families found ineligible for services. The State estimates that approximately 30% of families evaluated are ineligible for services.¹⁴ To be eligible for services, the infant or toddler must have a

33% delay in one area of development, or a 25 % delay in two or more areas of development. Although a family may not be eligible for services, the State must still pay for the cost of the evaluations to determine ineligibility, adding to the overall costs of the program.

Additionally, there are the costs of addressing critically unmet infrastructure and resource needs of the early intervention system. The Ocean County service coordination unit testified before the Department of Health and Senior Services on October 10, 2007, that currently service coordinators carry approximately 70 cases each. The recommended caseload is 35 cases. Caseloads will only increase as more families enter the system unless an investment in infrastructure and resources are made. Ocean County is just one of twenty-one service coordination units within the early intervention system.

2. Individuals with Disabilities Education Act

The Early Intervention System, currently Part C of the federal Individuals with Disabilities Education Act, was passed in 1986. It acknowledges the need to provide services early to children with disabilities. The law requires states that accept the federal money to provide services necessary to assist families in meeting the developmental needs of their children.¹⁵ In addition, it requires the system to identify needed services outside of the early intervention system and possible funding sources for these services.¹⁶ The law allows states to develop a family cost share when state law permits.¹⁷ However, certain aspects of the program must be free of charge to all families. These include: identification and referral, evaluations, individualized family service plan (IFSP) development, and service coordination.¹⁸ Therefore, where state law allows, a fee can be charged for direct services. But the law specifically indicates that services cannot be refused to families who cannot afford to pay a fee.¹⁹ The U.S. Department of Education provides no guidance on how a cost share program should be structured or what is defined as ability to pay.

3. Funding Allotment

New Jersey's early intervention program is projected to have a budget of approximately \$131 million for the 2008 state fiscal year that began on July 1, 2007.²⁰ Approximately \$11 million is federal IDEA funds.²¹ The State of New Jersey is contributing approximately \$97 million.²² In addition, there is a possible \$4.5 million from 2007 carryover Medicaid funds and \$12.9 million is projected from 2008 Medicaid funds.²³ Finally, the State is projecting five million dollars from the revised family cost share that passed in the State's 2008 fiscal year budget.²⁴ The previous cost share was a monthly cost share that was fixed based upon family income regardless of the number of hours of service received. The new cost share is based upon hours of services. Families pay an hourly cost share based upon income and family size that is capped at approximately four to five percent of a family's annual income.²⁵ When the cost share was initially proposed, many families opted to reduce services, leave the system or not enter in the first place. A family of four with an income of approximately \$70,000.00 a year would have a family cost share capped at \$3,500.00 a year.²⁶ Thus, the family would pay five

dollars a service hour with a maximum charge of \$241.76 a month.²⁷ The same family under the old system paid a flat fee of \$10 a month regardless of the number of service hours.²⁸

While the State of New Jersey provides substantial funding for the Early Intervention Program, the fiscal year 2009 is expected to be a very difficult year financially for the State. With expected increases in the number of eligible families and the severe budget difficulties facing the State and possible budget cuts, the State may be unable to provide the funding increases needed, and families will be unable to pick up the slack.

4. Medicaid

Medicaid is an important funding stream for the early intervention system. However, it appears as though New Jersey, unlike some other states, is not maximizing its use of Medicaid to fund its early intervention system. The IDEA specifically indicates that Medicaid funds should be expended prior to expending IDEA funds because IDEA funds are the payor of last resort.²⁹ The Department of Health and Senior Services should investigate two sources for increasing Medicaid funding for the early intervention system. The first is the EPSDT (Early Periodic Screening Diagnosis and Treatment) program. The second is a Medicaid Home and Community Based Services Waiver for Early Intervention Services.

EPSDT is a required Medicaid benefit that provides necessary medical treatment and services for all Medicaid eligible children from birth to age 21.³⁰ The benefit exists to ameliorate conditions that can impact a child's development and ability to learn.³¹ EPSDT provides early screening, diagnosis and treatment services to detect and treat medical problems at the outset.³² Any medically necessary service identified during a screening is covered and must be provided.³³ When done properly, the screening can identify developmental delays and provide information to families and medical providers regarding developmental milestones.

The EPSDT benefit is very broad and can cover an expansive array of early intervention services. However, New Jersey's participation and treatment rates for EPSDT services historically have been, and remain, inadequate. The participation rate for children ages birth to 18 was only 51% of all children in 2003.³⁴ The screening rates for children under age three are better but still low. In 2004, the screening rate for children under age one was 88% and for ages one to two was 71%.³⁵ The Departments of Health and Senior Services and Human Services should undertake a study to determine how more effectively to utilize EPSDT services to support the Early Intervention System.

Approximately five states currently have an Early Intervention Medicaid Waiver Program.³⁶ The programs vary in populations and services covered. Home and Community Based Waivers (1915(c) waivers) allow states flexibility to develop and implement programs allowing individuals to avoid institutionalization and remain in the community. States must demonstrate to the Center for Medicare and Medicaid Services (CMS) that waiver services are only provided to individuals eligible for institutional

placement. However, states have flexibility to design the waiver program and create a mix of services that will best meet the needs of the population served. The federal government must approve a state's definition of institutional level of care, but it does not require a significant level of medical need or functional limitation. New Jersey could adopt a definition that enables many families to benefit from a waiver program. Pennsylvania appears to have a comprehensive waiver and could be used as a potential model for New Jersey.

5. Mandatory Health Insurance Coverage

Currently, seven states have legislation requiring insurance coverage of early intervention services.³⁷ Four states require coverage of up to \$5000.00 a year and do not count the coverage towards the lifetime cap. The exception from the lifetime cap is important because families of very medically needed children will forego the use of insurance coverage for early intervention services in order to ensure coverage of services as the child ages.

While the use of private health insurance can generate funds for the early intervention system, it is limited by the Employee Retirement Income Security Act (ERISA).³⁸ ERISA precludes states from regulating self-insured health benefit plans. A self-insured benefit plan is one in which the employer bears the financial risk for medical claims. Self-insured benefit plans are becoming more common because employers can avoid the state-by-state regulation of insurance. However, mandatory insurance coverage of early intervention services could apply to the health insurance of state and local government employees, individually insured plans, and the private sector insured plans. The passage of such legislation in New Jersey would create an additional funding stream for the state's early intervention system.

6. Family Cost Share

Currently, 13 states plus New Jersey operate a family cost share structure in the early intervention program.³⁹ Each state defines ability to pay differently, ranging from annual income levels greater than 115% of the federal poverty standard to 350 % of the federal poverty standard. The payments also vary from monthly co-payments to co-payments per treatments. Some programs have annual caps as low as \$500 and exclude foster care children from the payment structure. Several states are reviewing their family cost share program for changes.

On August 1, 2007, New Jersey moved from a monthly co-payment structure to a co-payment per treatment program. Ability to pay has been defined as families above 350 percent of the federal poverty level. This equals an annual income of \$70,000 for a family of four. Families testified during the public hearings that this dramatic increase created by the change in co-payment structure will force families to choose between participating and not participating in the system or reducing services because the substantial increases are not affordable.

Many states that have mandatory insurance coverage or a Medicaid Waiver Program do not have a family cost share program. Ones that do, such as Massachusetts limit the cost share to \$500 per year for families.

7. History of Advocacy in New Jersey for Early Intervention Funding Sources

The Early Intervention Stakeholders Task Force, which was comprised of providers, advocates, service coordinators and other interested parties, developed a committee to study long-term funding options for the New Jersey Early Intervention System. Around 1999, a report was issued recommending among other things that the State pursue private health insurance coverage. The report was accepted by the Department Health and Senior Services and an agreement reached that the Department would pursue a legislative strategy to move forward with private health insurance coverage.

On February 3, 2005, relevant stakeholders were asked to testify before the Senate Health, Human Services and Senior Citizens regarding the early intervention system. A portion of this hearing was dedicated to alternate funding sources for the program. Advocates testified about the need to maximize Medicaid funding and require mandatory health insurance coverage of early intervention services.

Analysis

New Jersey does not have a long-term financing plan to ensure a financially healthy early intervention system. In the past it was necessary to pass supplemental budgets and borrow funds from other programs such as the Catastrophic Illness in Children Relief Fund to ensure the continuation of the program without interruption. Despite these drastic actions, the State of New Jersey has been unwilling to aggressively pursue alternate funding sources.

During the last several legislative sessions, bills were introduced to explore a possible Medicaid waiver and to look at mandatory insurance coverage. However, the Administration and the legislature have not deemed the issue to be a priority and passed these initiatives. While the Administration and legislature are seemingly reluctant to place the burden of increasing costs in the early intervention system on the State, they have failed to create a healthy and secure funding system. Instead they continually look to families to contribute more. With the last family cost share increase that was included in the FY 2008 state budget, many families saw their monthly family cost share increase by 300% or more. The burden of keeping the early intervention system afloat rests on the backs of families with disabilities.

It is well documented that the federal government has failed to fully fund any aspect of the IDEA, including Part C, the Early Intervention Program. The State of New Jersey needs to actively pursue additional dollars from the federal government as well as maximize its dollars from all possible Medicaid programs including a waiver. Among states that utilize a family cost share, New Jersey is on the higher end of the fee schedule.

The continued increase in family cost share contributions to address a faulty funding scheme has led to the creation of a system that discourages participation in the system and is punitive in nature for families who have children with developmental delays. Numerous families have spoken to NJP&A about the additional burdens of the increased family cost share. One family indicated that their child received 17 hours of services a month. Under the previous cost share structure the family paid \$23.00 a month for services. Under the new system, the family would pay \$289.00 a month for the same level of service. This was prohibitive for the family, and services were reduced to six hours per month.

Another family indicated that their child received eight hours of services a month. Under the previous cost share structure the family paid \$150.00 a month. Under the new system, the family would pay \$336.00 a month for the same level of service. This was prohibitive for the family, and services were reduced to four hours a month.

As a third example, another family indicated that their child was receiving 18 hours of services a month. Under the previous cost share structure the family paid \$104.00 a month. Under the new cost share system the family would pay \$485.00 a month for the same level of service. Because this was prohibitive for the family, services were reduced from 18 hours a month to eight hours a month.

According to information presented by the Department of Health and Senior Services to the State Interagency Coordinating Council in January 2007, the State sent notice to 3100 families affected by the change when the State initially attempted to change the family cost share system from a monthly co-pay to a per service co-pay in February 2007. In response to this notice, the State heard from approximately one-third of these families. Sixteen percent of families who responded indicated they were requesting an immediate IFSP meeting, presumably to reduce services. Two percent requested to receive only those services available at public expense. Seven percent terminated all participation in the early intervention system. Four percent indicated that they had already transitioned from the early intervention system. Finally, 71% of families responding indicated they were continuing with their current status. The changes impacted a significant number of families and many children are going without needed services.

Based upon discussions with families, NJP&A learned that the State's response to families who requested a payment plan for the increased cost is to counsel families to take fewer services. Discouraging participation in the early intervention system should not be an acceptable way to control costs in a program that continues to see increasing numbers of eligible families, particularly when studies and the legislature acknowledge the benefits of early intervention services.

The Department of Health and Senior Services released data on September 28, 2007, to the Early Intervention State Interagency Coordinating Council. The data contained the numbers of families who exited the early intervention system in 2007 due to the family cost share. The data indicates that from January 2007 through September 2007, 206 families who were receiving services left the program due to the family cost share

program. Seventy-five families refused to enter the program due to the family cost share program. The changes in the family cost share were initially published in January 2007. On February 1, 2007, the State postponed implementation of the change in family cost share until August 1, 2007.

The family cost share continues to be controversial in many respects. Furthermore, as evidenced by testimony provided by families during the October 2006 public hearings regarding the cost share and the October 2007 public hearings regarding the proposed regulations, the family cost share pits families against one another. Families who have children with significant disabilities questioned eligibility criteria. These families believe that instead of increasing the family cost share, the State should tighten eligibility requirements. Other families questioned the fairness of allowing any family to receive services free of charge. However, families are under the misperception that these are the only ways to address the fiscal concerns of the system. Families are unaware that the State has not pursued all possible funding sources.

Despite its stated willingness to pursue alternate funding sources when the Early Intervention Stakeholders Task Force released its report, the Department of Health and Senior Services has failed to aggressively pursue any alternate funding sources, including a Medicaid waiver and private health insurance coverage. The Department indicates that a Medicaid waiver would not yield funds because of the institutionalized level of care definition. However, this is not an accurate assessment, because as previously noted, several other states have a Medicaid waiver program that covers some early intervention services and there is no requirement that institutional care require a significant level of medical need or functional limitation. Furthermore, the Department of Health and Senior Services does not believe it is possible to pass insurance legislation in the State of New Jersey to mandate coverage of early intervention services.

Currently, there are multiple plans to provide expanded healthcare coverage to the residents of the State of New Jersey. This may present the perfect opportunity to bring a level of mandated health care coverage of early intervention services to the early intervention system. Any proposed expanded health coverage should ensure that early intervention services are covered and exempted from a lifetime cap. If passed, an expanded healthcare coverage program could certainly be a part of the creation of a financially healthy early intervention system within the State of New Jersey.

Conclusion

The State has yet to develop a comprehensive long term financing plan for the Early Intervention System. Such a plan is essential to sustain an early intervention system that continues to see double digit growth every year, especially in light of the severe budgetary restraints, the State expects to experience in fiscal year 2009 and thereafter. It is inappropriate and unacceptable for the State to try to contain costs by developing an early intervention family cost share program that discourages participation of families especially those who are most in need of the services. Instead the State must move to develop a financially secure early intervention system. The State should investigate and

pursue available funding options such as a Medicaid waiver and required health insurance coverage. Even if these alternate funding sources produce only limited increases, pursuit of alternate sources proves to families and advocates that the State is dedicated to the early intervention program and recognizes its importance. The politics of necessity and expediency hopefully will not derail such a vital program for children with disabilities and their families.

Without a long-term plan for financing it, the State will be unable to sustain a quality early intervention program providing necessary services to all the children and families who need these services. If the system continues to be plagued by shortfalls during each fiscal year, and parents are continually asked to fund more of the program, the system will be unable to maintain quality providers and keep families in the system. While it may be easiest to look to families to contribute more to the system, it is shortsighted. The State must move forward to develop a sound long-term financing plan to ensure the continued viability of a quality early intervention system. If the early intervention system deteriorates, New Jersey's most vulnerable children are at risk of unrecoverable losses that will impact the rest of their lives, costing the State much more in resources in the years to come. Therefore, it is imperative that the State of New Jersey pursue with a sense of urgency every possible funding source for the early intervention program, including a Medicaid waiver program and private health insurance coverage.

ENDNOTES

¹ Baily, Donald B., Ph.D., Kathleen Hebbeler, Ph.D., Donna Spiker, Ph.D., Anita Scarborough, Ph.D., Sangeeta Mallick, Ph.D., and Lauren Nelson, Ph.D., "Thirty-Six-Month Outcomes for Families of Children Who Have Disabilities and Participated in Early Intervention", Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina. February 2005.

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Karoly, Lynn A., "Investing in Our Children: What We Know and Don't Know About the Costs and Benefits of Early Childhood Interventions," Rand Corp. 1998.

² N.J.S.A. 26:1A-36.6

³ 20 U.S.C. § 1431, et. seq.

⁴ 20 U.S.C. § 1432

⁵ <http://www.state.nj.us/health/fhs/documents/intervention.pdf>

⁶ 34 C.F.R. § 303.520(b)

⁷ www.ideadata.org

⁸ Id.

⁹ <http://www.ideadata.org>

¹⁰ 20 U.S.C. § 1443

¹¹ http://www.nj.gov/health/fhs/documents/partc_apr05-06.pdf, p. 19, Annual Performance Report

¹² Id.

¹³ July 27, 2007 Meeting Minutes of the New Jersey State Interagency Coordinating Council

¹⁴ http://www.nj.gov/health/fhs/documents/partc_apr05-06.pdf, p. 20, Annual Performance Report

¹⁵ 20 U.S.C. § 1432(4)

¹⁶ 34 C.F.R. § 303.344(e)

¹⁷ 34 C.F.R. § 303.520(b)

¹⁸ 34 C.F.R. § 303.521(b)

¹⁹ 34 C.F.R. § 303.520(b)(3)

²⁰ New Jersey P.L. 2007, c. 111.

²¹ Id.

²² Id.

²³ Id.

²⁴ Id.

²⁵ Family Cost Share Guidelines, New Jersey Department of Health and Senior Services, August 2007.

²⁶ Id.

²⁷ Id.

²⁸ Id.

²⁹ 20 U.S.C. § 1440.

³⁰ 42 U.S.C. § 1396d

³¹ Id.

³² Id.

³³ Id.

³⁴ Form CMS-416 Annual EPSDT Participation Report (March 30, 2004) from the State of New Jersey to CMS.

³⁵ Id.

³⁶ <http://www.nectac.org/topics/finance/practices.asp#walver>

³⁷ <http://www.nectac.org/topics/finance/statelegis.asp>

³⁸ 29 U.S.C. § 1001, et.seq

³⁹ <http://www.nectac.org/topics/finance/finance.asp>