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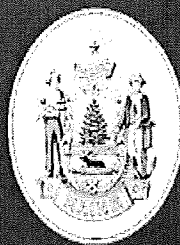
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Maine
Department of Education



Department of Health
and Human Services

Maine People Living
Safe, Healthy and Productive Lives

Early Identification and Early Intervention with Young Children with Autism

In response to legislative directive:
Resolve, To Establish a Statewide Protocol for the Early Detection and Treatment of Autism,
P.L. 2008, Chapter 200 (LD-1977)

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The Department of Health and Human Services
And
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March 2009

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Executive Summary

The 123rd Maine Legislature passed LD-1977 (P.L. 2008, Chapter 200), a Resolve to Establish a Statewide Protocol for the Early Detection and Treatment of Autism. This Resolve required the Maine Departments of Education (DOE) and Health and Human Services (DHHS) to establish a uniform statewide protocol for screening children for signs of autism, to examine treatment methods and, to examine the interdepartmental system for capacity and service availability. In accordance with the Resolve, this report describes the work that has been done and the process of establishing universal screening and improving Maine's early intervention system.

In the last couple of decades there has been a dramatic increase in the number of individuals identified with Autism and other Pervasive Developmental Disorders (PDDs) in Maine and across the country. The rapid increase in the number of individuals with PDDs is escalating the need to expand Maine's ability to serve this population. MaineCare Claims data indicates a 380% increase in individuals with PDD in the last nine years. This increase is reflected in a comparable 374% nine-year increase in the numbers of children receiving special education services in the Autism category. Both sets of statistics reflect an average growth of 17% annually.

The Governor and the Commissioners of the Departments of Health and Human Services, Education, and Labor have recognized the need to ensure that our service delivery systems adjust to meet the needs of people with PDD. In order to assure the most cost effective and efficient utilization of resources, the Commissioners are serving as the Steering Committee for a new PDD Systems Change Initiative. Using federal funds, a contract between the Maine Department of Education and the Maine Developmental Disabilities Council (MDDC) provides staff support and coordination for the Initiative. The Steering Committee charged the Initiative to examine the current systems of identifying young children with Autism and other PDDs and recommend ways to improve the efficiency of the process.

Since the Resolve was passed, State agency staff has accomplished a significant amount of work.

- Utilizing the PDD Systems Change Initiative Structure the Early Identification System was examined, screening tools and a screening schedule have been selected, and pilots to fully implement universal screening are currently being organized.
- DHHS and DOE have collaborated and created the PDD Evidence-Based-Practice Workgroup. The Workgroup is well under way examining current research about treatment methods that show evidence of effectiveness.
- The PDD Systems Change Initiative has a series of meetings scheduled to take place in the spring of 2009 to evaluate the current Early Intervention System in relation to how the different service systems work and are inter-related. The Initiative's Workgroup will identify ways collaboration between Child Developmental Services (CDS), DHHS, Office of Child and Family Services, Division of Children's Behavioral Health Services (CBHS), HeadStart and the service providers that serve children identified with PDD can improve: effective and quality

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intervention, timelines for children to obtain services, consistent coordination of services, comprehensive services that address all of a child's needs, and accessibility of services for all eligible children.

Definition of Autism

The Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revised (DSM-IV-TR) defines Pervasive Developmental Disorders as “severe and pervasive impairment in several areas of development” characterized by patterns of unusual social interaction, communication, and behaviors/interests. Five PDDs are included: Autistic Disorder (Autism), Asperger's Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS),¹ and two lower incidence disorders, Childhood Disintegrative Disorder and Rett's Disorder. According to the Autism Society of America and Autism Speaks, PDDs are lifelong, neurological developmental disabilities that profoundly affect the way a person comprehends, communicates and relates to others.^{2,3} The way individuals experience PDD can vary greatly in intensity and degree. Therefore, treatment and educational strategies must be highly individualized to meet the person's unique needs.

Autism was once considered a rare disorder. Now, according to the Center for Disease Control, Autism Spectrum Disorders are at epidemic levels affecting 1 in 150 children and are four times more likely to affect males.⁴

Universal Screening

In May 2008 the DHHS Office of LEAN Management hosted four full-day meetings to focus on the process of identifying children with Autism and other PDDs and to find ways to improve that process.

Families met the first day to share their stories and provide recommendations for improvement in the identification process. They described their experiences which included long wait times, multiple steps, and inconclusive answers or not receiving answers at all. The family stories documented that obtaining a diagnosis took an average of 31 months.

The PDD Early Identification Workgroup convened for three full-day meetings. This Workgroup included broad representation from physicians, psychologists, developmental clinicians, families, and advocates. The Workgroup also included representatives from Head Start, Child Development Services, and staff from various divisions of DHHS including Child Behavioral Health Services (CBHS) and Children with Special Health Needs (CSHN)

¹ Autism, Asperger's Disorder, and PDD-NOS are sometimes referred to as Autism Spectrum Disorders or ASD.

² http://www.autismspeaks.org/whatisit/index.php?WT.svl=Top_Nav accessed 1/29/2009

³ http://www.autism-society.org/site/PageServer?pagename=about_whatis, accessed 1/29/2009

⁴ www.cdc.gov/ncbddd/autism/index.htm, accessed 12/29/2008

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Universal Screening (Continued)

On the first day the PDD Early Identification Workgroup met, they outlined and examined the current system for identifying infants, toddlers, and young children with a PDD. The Workgroup concurred with the families' findings that there were a lot of loops and delays in the process of identifying children and due to these delays children are not being identified as early as possible. On the second day the Workgroup met, they designed an improved system. They determined that the ideal system would have all children be screened for PDDs at every well-child visit. If a problem is identified, physicians should refer the child to a diagnostician for evaluation and concurrently refer the family for services. On the third day that the Workgroups met, they designed a roadmap for activities to move the system closer to the ideal.

The Workgroup's recommendations included that Maine State agencies:

- Sponsor a public awareness/education campaign,
- Ensure the use of standardized tools for universal screening,
- Design and implement an efficient referral for diagnostic evaluation by a qualified medical provider, and
- Ensure prompt referral to early intervention services.

In July, the PDD Systems Change Initiative Steering Committee reviewed the work plan and approved the next phase of work to develop recommendations and to determine cost and resource implications for:

- Tools for universal screening,
- Process for referral to a diagnostician,
- Diagnostic evaluation components, and
- Required credentials for qualified diagnosticians.

Concurrently with the PDD Systems Change Initiative's focus on improving screening for PDDs in young children, the Maine Center for Disease Control, Division of Children with Special Health Needs (CSHN) had identified a need to enhance screening to enable earlier identification of social and/or emotional disorders in young children. CSHN wanted to augment the effectiveness of the current surveillance process used to measure developmental milestones in young children by enhancing screening for social and emotional disorders. After CSHN participated in the PDD Early Identification WorkGroup, they chose to partner with the Initiative in recognition of the shared goals of universal screening and early identification. Thus it was decided that a "best-practice" tool should be used to identify a broader range of social and emotional disorders, and a second "best-practice" tool should be used to screen for Autism and other PDDs when indicated.

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Universal Screening (Continued)

In November 2008, a diverse team of medical professionals, including pediatricians, developmental specialists, and general practitioners, nurse practitioners, and professionals in the fields of social work and speech pathology met to address protocols for universal screening. This group made the following recommendations:

- Screen all children using the Parents Evaluation Developmental Status (PEDS) screening tool at their 9- and 18-month well-child visits.
- Screen all children using the Modified Checklist for Autism in Toddlers (M-CHAT) screening tool at their 18- and 24-month well-child visits.
- Provide an automatic referral for services and further evaluation whenever a parent voices strong concern about his/her child's developmental progress.

The Workgroup also recommended that a minimum of four concurrent pilot projects lasting approximately six months be established to test how best to implement these requirements on a statewide basis. This will provide the basis for continuing support for medical offices to integrate the screening tools and schedule into their practices on a statewide basis.

There are multiple efforts underway to implement universal screening. For example:

- Implement Pilot Projects - The PDD Initiative Steering Committee has approved the pilot projects to field test use of the two screening tools. These pilots will provide information about how to implement the screening tools into daily use in busy medical offices. The pilots are scheduled to begin in early spring, 2009.
- Launch Universal Screening - The Maine Center for Disease Control will sponsor and host a Medical Conference on Autism at the Augusta Civic Center on May 12th, 2009. The purpose of the Conference is to educate physicians and other health care providers about the newest research on causes of and treatments for Autism, and to promote the new screening tools and schedule.
- Standardize Universal Screening - Maine's Center for Disease Control, Children with Special Health Needs has been approved for a grant from the Vermont Child Health Improvement Program for technical assistance to promote and establish the new screening tools and process on a statewide basis. They will do this by assisting Maine to build an Improvement Partnership. An Improvement Partnership is a nationally-recognized model that brings public and private entities together to collaborate and accomplish a specific public health goal. Maine's Improvement Partnership will work with medical practitioners and stakeholders in implementing universal screening, communicating and solving problems, and eventually institutionalizing this new process.

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Examination of Evidence-Based Treatment Models

As previously indicated, MaineCare Claims data and special education statistics indicate an alarming rise in the number of children diagnosed with PDDs in Maine over the last nine years. The increase in the number of children with ASD correlates to an increased demand for adequate and effective children's treatment services. Many of these services are delivered through the behavioral health and the education systems.

How does one know that the services provided are effective? The New Freedom Commission on Mental Health identified a wide gap between research and clinical practice as a significant barrier to provision of quality behavioral health care.⁵ Despite advances in our understanding of the brain and behavior, available research often takes far too long to be translated into the field.⁶ The behavioral health field has documented the effectiveness of certain treatments and services, which are commonly referred to as evidence-based practices (EBPs). However, a shortage of providers trained in EBPs, coupled with the serious challenges inherent in implementing such practices, has resulted in the relatively slow adoption of these scientifically validated services.⁷

In July 2008, the Department of Health and Human Services (DHHS) Children's Services Evidence-Based-Practice Advisory Committee decided to review the empirical evidence behind treatments and interventions for Autism Spectrum Disorder (ASD). Because services are delivered through both the behavioral health and education systems, the Advisory Committee invited the Department of Education (DOE) to partner with DHHS in this important process. A new Evidence-Based-Practice Workgroup (EBP Workgroup) was formed in August 2008 to review and assess treatments and interventions for their level of scientific evidence and potential challenges to implementing them in the community. The EBP Workgroup has broad stakeholder representation including: self-advocates, educators, the Autism Society of Maine, the Maine Developmental Disabilities Council, the Center for Community Inclusion and Disabilities Studies, families, providers, and public agency staff. To measure effectiveness they have adopted a systematic review process and a rating scale to rank the relative level of empirical evidence of treatments and services.

⁵ New Freedom commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

⁶ Institute of Medicine Committee on Quality of Health Care in America (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press.

⁷ New Freedom commission on Mental Health, *op. cit.*

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Examination of Evidence-Based Treatment Models (Continued)

In response to the pervasiveness of ASD, a number of treatments and interventions have been developed to address the needs of these children. The symptoms that a child with ASD may experience could impact the child across several areas of functioning, from social skills to activities of daily living. After a preliminary review of the literature and discussion, the workgroup elected to review treatments and services in the following topical areas:

- **A**pplied **B**ehavior **A**nalysis (ABA)
- Biomedical interventions
- **C**ognitive **B**ehavior **T**herapy (CBT)
- Developmental Social Pragmatic models
- Psychopharmacology
- **S**ocial **C**ommunication **E**motional **R**egulation **T**ransactional **S**upport (SCERTS®)
- Sensory Integration Therapy
- Social Skills Training
- Speech and Language Therapies
- **T**reatment and **E**ducation of **A**utistic and related **C**ommunication-handicapped **C**Hildren (TEACCH)

Literature reviews began in the fall of 2008 and are expected to continue for at least one year. Methods that have a higher level of evidence (if any) will also be reviewed for factors important to implementation, including necessary workforce training, supervision/consultation, fidelity monitoring, and cost. A report documenting the EBP Workgroup's final findings will be written and issued by the DHHS and the DOE. The report will be shared with families, policymakers, and other stakeholders.

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Examination of Interdepartmental System

The American Academy of Pediatrics [2007] has reported that studies indicate that early intervention services for young children with PDD could significantly improve the child's prognosis and should begin as early as 18 months of age.⁸ Research showed that almost all children with PDD directly benefited from early intervention therapies. The research further indicated that one-third of the children improved so much that their need for support was dramatically reduced.⁹

Identification of PDDs in infants, toddlers, and young children helps assure that appropriate early intervention services designed to address developmental issues are provided in a timely manner. Early intervention services designed to meet the child's unique needs may include a wide menu of services, such as:

- Therapies including speech, occupational, developmental, and physical therapy,
- Family support such as case management and counseling,
- Medical care for co-morbid disorders,
- Early education, and
- Social development.

P.L. 2008, Chapter 200 required DHHS and DOE to “examine the interdepartmental system for capacity and service availability.” The PDD Systems Change Initiative Steering Committee directed the Initiative to focus on the early intervention service systems. They requested that the Maine Developmental Disabilities Council work with the DHHS Office of LEAN Management to facilitate four full-day meetings using the LEAN philosophy. The LEAN philosophy provides a number of tools and techniques to help make processes visible so that improvements can be identified that will maximize the effort of the workforce and improve the quality of services to the consumer.

The first day will be a meeting with parents of young children with PDDs who are, or who have recently been, receiving early intervention services. The session's objective will be to capture parents' experiences with the early intervention service systems and obtain their input about how to improve the system. The second day the PDD Early Intervention Workgroup will convene. They will review the parents' experiences using the early intervention system. The group will then chart their experience with the process. The third day the Workgroup will determine what the ideal process would be. On the last day they will create an implementation plan to improve the current system. The four meetings are currently scheduled for April and May of 2009.

⁸ Myers MD, Scott M (2007) Management of Children with Autism Spectrum Disorders. Pediatrics <http://www.aap.org/pressroom/AutismMgmt.pdf> accessed 1/13/2009

⁹ Lord, Catherine (2001) Educating Children with Autism. National Academy Press ISBN: 0-309-07269-7

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Examination of Interdepartmental System (Continued)

The PDD Early Intervention Workgroup will include a diverse group of parents and professionals including representatives from:

- Department of Education
- Child Developmental Services
- DHHS, Office of Child and Family Services, Division of Children's Behavioral Health Services
- Head Start
- Maine Center for Disease Control, Division of Children with Special Health Needs
- Autism Society of Maine
- Speech Therapists/Pathologists
- Developmental Therapists
- Center for Community Inclusion and Disability Studies
- Parents
- Child Managers
- DHHS, Office of MaineCare Services
- Special Purpose Providers
- Developmental Specialists

Summary

Significant progress has been made over the last year to implement P.L. 2008, Chapter 200, A Resolve to Establish a Statewide Protocol for the Early Detection and Treatment of Autism. The Maine Departments of Education and Health and Human Services have collaborated to ensure successful statewide implementation. The Departments have organized a PDD Evidence Based Practice Workgroup to examine and recommend treatment methods that show evidence of effectiveness. In addition, in the spring of 2009 there will be a series of meetings scheduled to examine the current early intervention system and identify methods to improve coordination and collaboration between service systems.