

## THE VIEWS OF MAINE STAKEHOLDERS



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### Introduction

Over the past decade, Maine's behavioral health system has made significant improvements in accessibility and service delivery for Maine's children, youth and families. At the Maine Children's Alliance, I oversee the Maine Child Welfare Services Ombudsman Program, which enables me to work directly with children and families, helping them navigate the child welfare system. In this work, I have been pleased to support the goals of the Office of Child and Family Services' Divisions of Child Welfare and Children's Behavioral Health Services as they strive to integrate services for children and families in child welfare. Significant benefits have resulted from children being placed with kinship families, and we hope to see more of such positive trends continue.

Maine's behavioral health system faces additional challenges as it works to incorporate behavioral health services into our early childhood system. An important discussion is underway to determine how Child Development Services in the Department of Education will be better integrated in this system. The Division of Early Childhood in the Office of Child and Family Services is collaborating with the Maine Children's Growth Council, providers and families to find the best ways to support these critical early childhood programs.

We offer this guide as a reference to help legislators and other policymakers understand the behavioral health issues facing our children and their families. The Maine Children's Alliance compiled the observations and recommendations of eight organizations involved with mental health services for Maine children. The sections in this guide present the perspective of family groups, advocates and service providers. Their contributions help form a picture of the resources and challenges in Maine's behavioral health system. Several common themes emerge across the stakeholder groups and these are summarized on the last page. We hope you will use this guide as a starting point for further thoughtful discussion.

Dean Crocker

President and CEO, Maine Children's Alliance

of Dean Crocker

This research was funded by the Maine Health Access Foundation. We thank them for their support but acknowledge that the findings and conclusions presented in this report are those of the stakeholders represented, as compiled by the Maine Children's Alliance, and do not necessarily reflect the opinions of the Foundation.

Established in 1984, the Maine Parent Federation, Inc. is a statewide private non-profit organization that provides information, advocacy, education, and training to parents and professionals to benefit all children. Through our projects, individuals receive information about: specific disabilities, parenting, education, services and support groups available to assist families and professionals within the home, school and community.

The stigma associated with a mental health diagnosis continues to have an impact on a family's decision to seek help for their child.

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#### MAINE PARENT FEDERATION, INC.

Availability of services is not keeping pace with the number of children and youth in Maine who are identified with mental health issues. This problem exists across the full range of in-home and community-based services that support families. These areas include evaluations, treatment options and support services. Because of the lack of services, many families contact their local law enforcement agency for help with their child because it is the "best," and often only, option available to them in their community.

When adequate services are not provided, the outcome for many children with mental illness is not good. We are concerned about the number of children with mental illness who are dropping out of school. The mental health issues for this population include depression, anxiety, low self-esteem and poor ability to adapt. The long-term outcome can be seen when we look at the incarcerated population in Maine. A large percent of incarcerated individuals are high school dropouts, have a mental health diagnosis, or both. We need to address children's mental health issues early in life, so they do not result in negative consequences later.

Maine needs to do more to reach out and educate the public about mental illness. Children and families still experience the stigma associated with a mental health diagnosis so they may not seek support services, even when available. Related to the issue of stigma is the increase in the number of children and youth who are being bullied, in person and on-line, because they may be perceived as different. There are too many news stories about children and youth who have been victims of bullying who attempt suicide, sometimes successfully, drop out of school, or become involved in the juvenile justice system. We could change these outcomes for children by doing a better job of raising public awareness.

Families need access to affordable health care that addresses both emotional and physical health issues. We need to ensure that both the physical and mental health needs of children and youth are addressed in one service delivery system. Currently, their needs are met in two separate systems which do not serve the "whole" child.

#### MAINE ASSOCIATION FOR INFANT MENTAL HEALTH

Infants, toddlers and young children do have emotional and behavioral health challenges that, as with any age sector, can become more serious later in life if we fail to address them.

Children's inherent vulnerability puts them at particular risk of emotional and mental health challenges when adults are unable or unwilling to provide protection and support because of alcoholism, drug use, domestic violence, incarceration, death, divorce, or mental illness.

Children's exposure to these conditions early in life can lead to emotional and mental health problems and, left untreated, can lead to long-lasting problems in school and in their adult life. We want legislators and other policy makers to understand that these and other types of early negative experiences do have lasting effects, including having an impact on the number of children that drop out of high school and develop adult mental health problems. A belief that "they won't remember" because they are so young is contradicted by research studies.

Maine can prevent these long-lasting negative effects on adults by investing early in the healthy development of infants, toddlers and young children. When we make this critical investment, we provide the foundation for our children to succeed as adults. If we want Maine to compete and prosper economically, policy makers often state that we must increase high school and college graduation rates. Until we invest in improving the quality of in-home and community environments and the health of relations that infants and young children have with adults, Maine will not achieve the success we seek in our educational, economic, financial, political and policy undertakings.

We recommend investing in the A-I-M-S system of practice that focuses on the emotional health of children from birth to age 5. A-I-M-S is an acronym for the four domains of children's emotional health:

Attachment = parent/child/family feelings Interaction = parent/child/family behaviors Mastery = parent/child/family capabilities Support = parent/child/family resources

The A-I-M-S system of practice guides professional practice that will ensure:

- Babies/young children have positive social and emotional attachments to their primary caregivers;
- They have positive, loving interactions with the adults in their lives;
- They achieve mastery of a wide variety of skills during their early years; likewise, their parents need to "master" positive parenting skills; and
- Babies, young children and parents have the support of their extended family and the community to grow healthy and resilient children.

The AIMS: Developmental Indicators of Emotional Health is a system of practice designed to enhance the emotional development and well being of young children, from birth to age five, and their families. Its primary purpose is to have a positive impact on the way physicians, nurses, early educators, and mental health providers incorporate and support emotional health in early childhood.

Founded in 1982, the Maine Association for Infant Mental Health brings special knowledge to Maine's resources for families to help them grow mentally and physically resilient children into adulthood. Through the delivery of training and education, we work to increase members' ability to respond to the optimal development and wellness of infants and their families and to facilitate collaboration among groups, agencies and individuals that serve them.

Early childhood is a period when infants and toddlers are most vulnerable because they are dependent on the quality of protection, development and nurturing provided by adults.

MAINE ASSOCIATION FOR INFANT MENTAL HEALTH Debra Nugent Johnston, Executive Coordinator 592 Sawyer Road Greene, ME 04236 (207) 375-8184 www.infantmentalhealth.org The Maine Head Start
Directors Association
consists of 12 grantees.
We work to develop a
statewide system that
supports strong, quality
early care and education
tailored to meet the unique
needs of the communities we
serve. Head Start services
include early education for
infants, toddlers and pre-school
children.

Our teachers are working increasingly with children whose mental health needs have an impact on their ability to follow daily routines, participate in classroom activities, and interact socially with peers.

KENNEBEC VALLEY COMMUNITY ACTION PROGRAM (KVCAP) Kathy Colfer, Child & Family Services Director 97 Water Street Waterville, ME 04901 (207) 859-1613

#### MAINE HEAD START DIRECTORS ASSOCIATION

We are seeing an increase in aggressive behaviors by children in our classrooms. These trends include:

- An increase in bullying, aggressive physical and verbal behaviors, including biting staff and other children; hitting, kicking, spitting, scratching, destroying other children's work; and laughing at other children's sadness.
- An increase in the number of young children who require mental health services due to stressors in the home environment. Children react in anger, have poor impulse control and emotional outbursts, greater anxiety, difficulty calming themselves, and may harm or kill a pet.
- An increase in the number of referrals for behavioral concerns to Child Development Services, to community mental health services, and to Child Protective Services.

The mental health and behavioral support needs of children require a significant level of support from teachers and Head Start Programs. Teachers are working with an increasing number of children whose mental health needs have a significant impact on their ability to participate in healthy ways, to learn so they are ready for school when the time comes and to develop the social and emotional health skills they will need to succeed in school and in life. Teachers spend a significant amount of time supporting children as they develop these fundamental skills. Teachers require more regular support from program managers and mental health consultants, and they are making more requests for 1:1 education technicians.

While this guide is focused on children's mental health, we cannot ignore the parents whose own stress/anxiety and mental health diagnoses impede their ability to parent. The children's mental health needs must be addressed within the context of the family and their home life. The trends involving parents include an increase in:

- The number of reports made to DHHS for physical abuse and neglect, with more out-of-home placements of children.
- The number of children whose primary caregiver is a grandparent, who often does not have adequate resources to care for them.
- Parental stress/anxiety caused by current economic conditions, with few employment prospects, which is affecting the children.
- The number of homes in which parents are involved with alcohol, drugs and domestic violence.
- The number of parents who are absent due to incarceration, substance abuse, death, divorce and separation.

#### **Head Start Programs in Maine**

Aroostook Community Action Program, P.O. Box 1116 (771 Main St.), Presque Isle, ME 04769. Office: 768-3045 Androscoggin Head Start & Child Care, Coburn School – Bates Street, Lewiston, ME 04240. Office: 795-4040 Child & Family Opportunities, Inc., P.O. Box 648, Ellsworth, ME 04605. Office: 667-2995 Community Concepts, Inc., P.O. Box 278, South Paris, ME 04281. Office: 739-6574 Kennebec Valley Community Action Program, 97 Water Street, Waterville, ME 04901. Office: 859-1618 Mid-Coast Maine Community Action, 34 Wing Farm Parkway, Bath, ME 04530. Office: 442-7963 Penquis CAP, P.O. Box 1162, Bangor, ME 04402. Office: 973-3531 PROP, 510 Cumberland Avenue, Portland, ME 04101. Office: 874-1140 Southern Kennebec Child Development Corporation, 337Maine Avenue, Farmingdale, ME 04344 Office: 582-3110 Waldo County Head Start, P.O. Box 130, Belfast, ME 04915. Office: 338-3827 York County Head Start, P.O. Box 72, Sanford, ME 04073. Office: 324-5762

#### MAINE ASSOCIATION OF MENTAL HEALTH SERVICES

Children are entering treatment at younger ages with behavioral symptoms at levels that threaten their safety and the safety of their families and communities. The children we serve are more violent than ever before and come from families that are struggling more and more with poverty, hunger, family trauma, substance abuse and criminal behaviors.

Proactive, evidence-based, outcome-oriented, family-centered interventions help keep children safely in their homes and communities. Research shows that these types of treatment interventions not only achieve the best outcomes, but are also the most cost effective.

Rather than waiting to treat serious and chronic mental health issues reactively, more efforts must be made to respond proactively and preventatively. Children and families need earlier intervention and education regarding healthy child and adolescent development and screening for behavioral health issues. They also need increased and immediate access to treatment services when behavioral symptoms first appear. Resources are currently rationed, with the largest portion being spent on less-effective short-term and specialty care and the smallest portion being invested in highly effective preventative care. We advocate for a reprioritization of resources to better support interventions in children's homes, communities and schools, with a smaller percentage going to hospitals and jails. Increasing focus on preventative care and devoting resources to support Maine's children and families will help keep Maine's future bright.

#### **MAMHS Members:**

Alternative Services, Inc. Androscoggin Home Care & Hospice Aroostook Mental Health Center Catholic Charities Maine Charlotte White Center Community Care Community Concepts Community Health & Counseling Common Ties Mental Health Crisis & Counseling Day One Harbor Family Services Kennebec Behavioral Health Motivational Services NFI North, Inc. Providence Service Corporation of Maine Rumford Group Homes, Inc. Stepping Stones Sunrise Opportunities Tri-County Mental Health Volunteers of America Wings for Children & Family Youth & Family Services

The Maine Association of Mental Health Services advocates for the collective interests of mental health organizations in Maine. We analyze trends in the delivery and financing of mental health services, identify public mental health policy issues, apprise our members of research findings and best practices in the delivery of mental health services, foster collaboration, provide consultation and technical assistance, and promote effective management practices.

The children we serve are more violent than ever before, but the mental health/behavioral health system is structured to react to medical disorders instead of supporting preventative efforts needed to help children successfully develop into healthy adults.

MAINE ASSOCIATION OF MENTAL HEALTH SERVICES Bart Beattie, LCSW Chair, Children Services Committee 45 Memorial Circle, Suite 103 Augusta ME 04330 (207) 621-4111 www.mamhs.org

Disability Rights Center is an independent non-profit agency focused on protection and advocacy for people with disabilities. Our services include assisting individuals so they can advocate on their own behalf, representing individuals at meetings and hearings, and providing training on rights and advocacy skills. We work collaboratively with other agencies to effect systemic changes that enhance the quality of life for people with disabilities.

...children with
disabilities whose needs
could be met in public
schools are being placed
in more expensive,
segregated private
programs.

DISABILITY RIGHTS CENTER Kim Moody, Executive Director P.O. Box 2007 Augusta, Maine 04338-2007 (207) 626-2774 www.drcme.org

#### **DISABILITY RIGHTS CENTER**

Students with disabilities are not attending school. Disability Rights Center handles a number of cases every year involving children with disabilities that impact behavior who are not attending school. These children are not suspended or expelled or ill, but are home without a program because the school district does not know how to meet their needs. These children will not graduate from high school and become successful citizens if they do not attend school.

Potential solutions include: better training for school staff in appropriate educational and disciplinary methods for children with mental health diagnoses; and greater access to behavioral expertise for school districts. One suggested model is that districts share the services of a behavioral expert who can consult with districts on an as-needed basis.

Students with disabilities are not attending school for a full day. Students are placed on a partial day program or are sent home from school frequently because the district is unable to meet their needs due to a lack of expertise or staff shortages. Parents' jobs are placed in jeopardy because they must leave work frequently on an unscheduled basis to pick up their children. In addition to the solutions listed above, greater staff support (e.g. trained educational technicians) would be helpful so that children are not sent home due to staff shortages. An example of this is when there are two partial-day children who share an educational technician, so that when one child is sent home during the day, the other one must also stay home.

Students with disabilities whose needs could be met in public school are being placed out of district in more expensive private schools due to lack of programming options. Better training, support and regulation regarding school-based day treatment and other school-based mental health services will allow students to remain in their local schools, and will avoid placement of these children in programs outside of their districts.

There is increased overuse and inappropriate use of restraint and seclusion in public schools. The lack of behavioral expertise available and staff shortages in some of Maine's public schools have led to increased and inappropriate use of restraint and seclusion. School staff who are insufficiently trained and inadequately supported resort to dangerous methods to control behavior because they do not have the skills to de-escalate and prevent serious and dangerous misbehavior before it occurs.

Potential solutions include: better staff training in de-escalation techniques and positive behavior supports to reduce the severity of behavioral incidents; more programming options so students are placed in a setting that meets their needs; and clear regulation so that staff know what their responsibilities are when circumstances arise where there is a need to control student behavior to ensure safety.

Ensure best clinical practice in the prescription of anti-psychotic medication. Maine Department of Health and Human Services (DHHS) participated in a multi-state study that evaluated anti-psychotic prescription practices involving children enrolled in MaineCare. DHHS should provide education and support to medical practitioners to ensure that they adhere to best practices.

*Transitional services should be well coordinated.* Children with mental health diagnoses experience transition not only when moving into adulthood and adults services, but also frequently during childhood and adolescence when moving from one level of service to another, such as out of a hospital or residential setting. All transitions need to be carefully planned in advance so that they can be well coordinated, explained and appropriately supported to avoid traumatic crises and costly hospital admissions.

### JOBS FOR MAINE'S GRADUATES (MAINE YOUTH DEVELOPMENT CENTERS)

Many youth within the Jobs for Maine's Graduates programs might have avoided the justice system altogether, if they had been able to access mental health services. Untreated mental health problems can affect all areas of youth's lives, including decision-making, self-image and life choices. Providing community-based services and support to children and youth with mental health needs is a preventive measure that promotes public safety and reduces recidivism for youth who do come in contact with the police. Without community-based resources, some of these young people, ages 15 -20, are incarcerated where conditions may exacerbate mental health issues and behavioral problems. Reform is imperative in order to provide mental health screening, comprehensive evaluation and appropriate treatment for these young people. Some common disorders among children in the justice system are depression, anxiety disorders, post traumatic stress disorder, attention deficit hyperactivity disorder, conduct disorder, schizophrenia, autism spectrum disorders and mental retardation. Youth with mild or undiagnosed developmental disabilities are often mistakenly identified as having behavioral problems because they exhibit poor impulse control and negative social interaction. Those with learning disabilities may also feel marginalized, contributing to low self-esteem and acting out. Many of these conditions are exacerbated by histories of physical, sexual and emotional abuse, parental drug or alcohol use, poor school performance or truancy and family conflict.

Without the necessary treatment, juvenile offenders with mental health needs are more likely to re-offend and return to the juvenile justice system. Children and youth who come in contact with the juvenile justice system should receive effective vocational and independent living skills training, education and special education, health and mental health services, social services and substance abuse treatment. Their families should have training and support to ensure youth continue to function responsibly after discharge from juvenile facilities. Once released from the juvenile justice system, where they have received assistance, they may not have access to the necessary community mental health services for continued treatment. This starts a vicious cycle.

Since 1994, Jobs for Maine's Graduates has provided more than 20,000 students at the highest risk of disengaging from school or dropping out of school with the skills and motivation needed to succeed in higher education and the workforce. Through our programs, high-school and middle-school students discover their individual talents, develop skills, and seize opportunities to achieve their personal potential. These comments speak to a special program of Jobs for Maine's Graduates for youth in juvenile corrections facilities.

Some children are
caught in a vicious cycle
of needing mental health
services, entering the
juvenile justice system
and receiving assistance,
then being released
without access to the
community mental
health services necessary
for continued treatment.

JOBS FOR MAINE'S GRADUATES Carlo Bufano, Development Mgr. 45 Commerce Drive, Suite 9 Augusta, Maine 04330 (207) 620-7180 www.jmg.org NAMI-Maine was established in 1984 as a grassroots advocacy organization dedicated to improving the lives of individuals and families affected by mental illness. We provide public education to focus attention on mental illness as a high priority, offer support groups, training and education as a pathway to recovery, empowerment and wellness, and serve as a voice of advocacy in state government for people living with mental illness in Maine.

The scientific community has established what works to support children with mental illness and prevent negative outcomes, but we are not investing in what works.

NAMI MAINE
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#### **NATIONAL ALLIANCE ON MENTAL ILLNESS - MAINE**

Make available, throughout Maine, practices that have been found to be effective through research on children with mental illnesses and behavioral difficulties. These effective, evidence-based practices include High Fidelity Wraparound, Multi Systemic Therapy, Family Focused Therapy, Cognitive Behavioral Therapy and trauma focused CBT, STEP, Collaborative Problem Solving and others.

Screening for mental illness should be part of pediatric and primary care visits. Maine can prevent more serious issues from emerging by encouraging primary care providers to provide early intervention and treatment, including screening for depression, suicide, autism, post-partum depression and anxiety. At every opportunity, primary care providers should screen and assess children and youth for behavioral health issues and either provide treatment or refer for mental health services.

We need a comprehensive service approach to enhance community, physician- and school-based protocols for identification and referral of people with mental illness. Children, youth and families need to know the resources available to them, no matter how or where they are identified as having a need for mental health services (e.g., at their school, through juvenile justice, through behavioral health services, or through their primary care doctor). This would require working across systems and across state departments to ensure an integrated and comprehensive system of care and support for children and their families.

Youth with behavioral issues who are incarcerated would be helped more effectively if they were diverted to treatment for mental illness and substance abuse. It would be more cost effective and produce better outcomes to connect these young people with treatment and support for them and their families in their community, rather than detaining children and youth with behavioral health needs.

Provide law enforcement and first responders with a basic understanding of child and adolescent development, psychiatric disorders, mental retardation and developmental disabilities, suicide prevention and self-injurious behavior. These critical tools and techniques help public safety professionals de-escalate situations in which youth experience mental health crises; they also facilitate getting youth connected with the help and support they need in their community.

Seamless connection to adult services for transition-aged youth. In many regions of the state, children's services do not ensure the connection of youth to support and services as they become adults. Many times "transition services" are unavailable, fragmented or families are not aware of how to access these services. The story below demonstrates this disconnect.

John was supported for many years with special education services through the school, and was on course to graduate. School, family, community and John all worked very hard to help him to finish his education. Days before graduation, John failed to complete his work, and did not graduate. Subsequently, children's case management discharged him without making the referral to adult services. His case management provider said that "due to budget cuts" the case manager was no longer employed with the agency and would not be replaced. John had a plan to work after graduation, but was not linked to Vocational Rehabilitation for assistance in job placement, based on his skills. Today, John is not working, is without community or financial supports, disengaged from family and his school, and supporting roommates on his disability income.

#### **G.E.A.R. PARENT NETWORK**

Currently 8.5 million youth age 18 and under are uninsured. And among those with private or public insurance, mental health coverage frequently is minimal or non-existent. As long as this fact remains true, children and youth who are affected by mental illness and other emotional disorders are vulnerable.

Nearly 5 million American children and adolescents suffer from a serious mental illness (one that significantly interferes with their day-to-day life).

15,000 American children with psychiatric disorders were improperly incarcerated last year because no mental health services were available.

According to an Institute of Medicine (IOM) report on mental health prevention and promotion released in February 2009, 50% of individuals with a mental health diagnosis have onset by age 14, and 75% by age 24. The IOM also reported that mental, emotional and behavioral disorders cost the nation about \$247 billion annually in treatment and lost productivity. Therefore, given the early onset of these disorders and their subsequent costs, investments in early intervention programs, especially those that better connect health and education systems, should be a priority in Maine.

According to the Ad Council, only 26% of the population is generally caring and sympathetic towards individuals with mental illness. This lack of sympathy leads to many issues our children must face such as being victims of bullying and discrimination. This discrimination leads to isolation, social distancing and the lack of availability of services and supports. This attitude keeps children and youth with mental health challenges and their families from seeking the help they need. We must promote positive mental health in an effort to educate and change the public perception. Our children and young people can get better and reach recovery and their potential.

G.E.A.R. Parent Network staff is comprised of parents who have personal experience with the system of care for children's mental health. This unique perspective is helpful in assisting other parents navigate the system and in connecting them with appropriate supports in a timely and effective manner. When parents can find the right support at the right time the system is not over utilized. Families who are familiar and confident with the system are less likely to use inappropriate or more expensive acute care services and are more likely to use options that are preventative and proactive.

#### **Our Mission:**

"To empower parents of children with behavioral health concerns, to affect life decisions based on their families' individual strengths and needs."

G.E.A.R. Parent Network, the place where Gaining **Empowerment Allows Results** (G.E.A.R.), was started informally in 1988 by a group of parents in Penobscot County and was established in 1992 under Crisis & Counseling Centers as the agency's statewide, parent-run program. G.E.A.R. is Maine's chapter of the National Federation of Families for Children's Mental Health. Thanks to funding from the Office of Children's Services of Maine's Department of Health and Human Services, G.E.A.R.'s supports and resources are free of charge to parents who have children with behavioral health issues.

Investments in early intervention programs, especially those that better connect health and education systems, should be a priority in Maine.

G.E.A.R. Parent Network Carol Tiernan, Director www.gearparentnetwork.org

# SUMMARY: Challenges and Issues

Contributors to this guide raise important issues for policy makers to consider as they develop their positions on important public policies. Key points within this report include:

- ▶ Intervention is not happening quickly enough for many children and their families, nor is the range of community support options sufficient.
- ► Children at very young ages are exhibiting serious and even violent behavioral challenges.
- ▶ Families are facing increasingly serious challenges in the areas of poverty and unemployment, domestic violence, substance abuse and mental illness.
- ▶ Failure to provide the right help at the right time and in the right place results in more severe symptoms later, requiring more expensive interventions.
- ▶ Screening of children for behavioral health challenges is often insufficient or non-existent, contributing to the increasingly severe symptoms, including violence, we are now seeing.
- ▶ Physical and behavioral health services must be made to work as a community-based team in concert with education and juvenile justice.
- ▶ Upon release from the juvenile justice system, youth often have little or no follow-up, losing important gains made as a result of services received during incarceration.
- ▶ Services often end when youth transition to adulthood. Services must be available, and transition to the adult system must be seamless.
- ▶ We know what works but, too often, the system does not support what works.



The Maine Children's Alliance advocates for sound public policies to improve the lives of all Maine's children, youth and families.

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