

Unclaimed Children Revisited

The Status of Children's Mental Health Policy in the United States

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The National Center for Children in Poverty (NCCP) is the nation's leading public policy center dedicated to promoting the economic security, health, and well-being of America's low-income families and children. Using research to inform policy and practice, NCCP seeks to advance family-oriented solutions and the strategic use of public resources at the state and national levels to ensure positive outcomes for the next generation. Founded in 1989 as a division of the Mailman School of Public Health at Columbia University, NCCP is a nonpartisan, public interest research organization.

UNCLAIMED CHILDREN REVISITED: The Status of Children's Mental Health Policy in the United States

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The needs of children and youth who experience mental health difficulties, as well as the needs of their families, cannot be addressed adequately without solid policy foundations at both state and federal levels. *Unclaimed Children Revisited: The Status of Children's Mental Health Policy in the United States* aims to document and assess how well child mental health policies across the 50 states and three territories respond to the needs of children and youth with mental health problems, those at risk, and their families. Comprising a national study and four sub-studies, this report presents a range of data collected from service users, providers, family members, youth advocates, and state and county system leaders across the child serving spectrum. The report then uses these data to identify state- and federal-level policy implications and recommendations with the goal of promoting improved mental health service delivery through policy reform.

LEAD AUTHORS

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EXECUTIVE SUMMARY

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Over 25 years ago Jane Knitzer, in the report *Unclaimed Children: The Failure of Public Responsibility to Children in Need of Mental Health Services*, documented policy and program disconnects that meant children and youth with mental health needs and their families did not get the services they needed.* That report, along with family advocacy, served as a spur to improve service delivery for the most troubled children. In the intervening years, there has also been an explosion of knowledge about the biological and social determinants of children's mental health issues, new understandings of how children and their problems develop, and new ways of providing preventive and treatment services. And so, more than a quarter of a century later, NCCP posed the central question for today's children's mental health system: to what extent is this new knowledge incorporated into the policy and practice frameworks governing children's mental health?

This report is based on a study that documents how current child mental health policies across the United States respond to the needs of children and youth with mental health problems, those at risk, and their families. Our aim was to identify best policy practices that support family- and youth-focused, research-informed, developmentally appropriate, culturally and linguistically competent services and supports.

Our Questions

The study sought to answer the following questions:

1. Overall, how well are states serving children and youth with mental health conditions?
2. How are states moving toward a child mental health system that is guided by a public health approach that integrates prevention, early intervention, and treatment?
3. How are states addressing, in an age-appropriate manner, the mental health needs of children and youth, through a public health lens?
4. How are states improving the systems for service delivery and supports for children and youth with serious emotional disorders and their families?
5. How are mental health practices across the age-span guided by evidence of effectiveness?
6. How well do states respond to the need for culturally- and linguistically-competent services and systems to meet the needs of children, youth, and their families?
7. How well do states meet the need for family- and youth-responsive services and systems to meet the needs of children, youth, and their families?
8. How do states improve service delivery through infrastructure-related supports, fiscal policy and accountability measures?
9. What policy barriers and opportunities exist for states that try to improve their service systems?

*Knitzer, J. (1982). *Unclaimed Children: The Failure of Public Responsibility to Children in Need of Mental Health Services*. Washington, DC: Children's Defense Fund.

Our Approach

To answer these questions, NCCP investigators used multiple methods to collect data. First, we conducted a state policy study (with responses from 53 jurisdictions). In addition to hearing directly from state child mental health directors through a survey, information was gathered from service users, providers, family members, youth advocates, and county system leaders across the child serving spectrum. Four sub-studies informed this report. These include:

- ◆ A survey of 19 mental health advocacy organizations in the United States that are under the umbrella of Mental Health America to complement the national survey;
- ◆ A case study of over 700 respondents in 11 counties in California;
- ◆ A case study of over 100 key informants from child behavioral health systems in six Michigan counties focused on outcomes management; and
- ◆ A survey of over 80 child mental health directors and multicultural directors focused on cultural and linguistic competence.

Major Findings

States are struggling to respond to the needs of children with mental health conditions. Children with complex needs such as co-occurring disorders pose the most difficult challenges. But while states have implemented some strategies, they generally lack the scope to address the need.

- ◆ Forty-one states (77%) reported that there are groups of children and youth with serious mental health problems that they serve well, but 12 states (22%) reported that there are *no* children and youth with serious mental health problems that they serve well.

States are moving toward a developmentally appropriate public health framework but progress is slow, with different interpretations about what it means to create a balanced service delivery system.

- ◆ Thirty-nine states reported that they have taken steps to move to a more public health oriented system, however states varied in their interpretation of what that means.

Toward a Developmentally Appropriate Public Health Mental Health Framework

A developmentally appropriate system of care should be marked by at least eight core components:

- A balance in the use of resources to encompass all age groups
- A balance in the array of services encompassing prevention, early intervention, and treatment, including for those with the most serious, complex problems
 - Discrete, age-appropriate, research-informed services for young children and their families from pre-natal through age five or even eight
 - Discrete, age-appropriate, research-informed services for school-age children differentiated for elementary school and high-school-aged youth
 - Discrete, age-appropriate, research-informed services for youth transitioning to adulthood
- Age-appropriate family supportive services embedded across all services, including those for mentally ill adults
- Culturally responsive services embedded across all prevention, early intervention and treatment services
- Adheres to system of care principles.

- ◆ In nine of these states, mental health advocates independently reported that such a shift is not evident.

States vary in their efforts to meet the mental health needs of children and youth in an age-appropriate manner. Only a handful of states reported statewide efforts across the age-span.

- ◆ Overall, 42 states reported one or more state-wide initiatives on behalf of young children, school-aged children, and/or youth transitioning to adulthood; but
- ◆ Only seven states reported consistent support and funding for children and youth across the age-span, among young children, school-age children, and youth transitioning to adulthood.

For young children (birth to age 5):

- ◆ Forty-four states reported that they implement one or more initiatives that are designed to improve services and supports; but
- ◆ Half of these states reported that these initiatives are statewide.

For school-age children and youth, (6-18):

- ◆ Forty-seven states reported that they are actively involved in supporting school-based mental health initiatives designed to improve services and supports; and

- ◆ Half of these states reported that these initiatives are statewide.

For young adults, (18-26):

- ◆ Forty-four states reported that they are involved in supporting one or more initiatives for young adults with mental health problems transitioning to adulthood; and
- ◆ Nearly 60% of these states reported that their initiatives are statewide.

States have incorporated system of care values and principles into the service delivery system to support children and youth with serious emotional disorders and their families but only a few states have embedded the principles in regulatory or legislative structures.

- ◆ Fifty states (94%) reported that they have incorporated the system of care philosophy and values for children and youth with serious emotional disorders in their delivery systems.
- ◆ However, 18 states reported specific steps to make operational and sustain these efforts through legislation and regulation, practice standards, and strategic planning.

System of Care Values and Principles

System of Care Values

- Child driven and family focused
- Community-based
- Culturally and linguistically competent
- Family driven

System of Care Principles

Access to:

- Comprehensive service array
- Individualized services based on individualized needs and service plans
- Clinically-appropriate, least-restrictive service settings
- Families as full partners in service planning, decision-making, and delivery
- Integrated service delivery
- Case coordination and seamless service delivery
- Early identification and intervention
- Seamless transitions to adulthood
- Culturally responsive services and supports
- Youth and family rights and advocacy

Source:

Lourie, I. 1994. *Principles of Local System of Development: For Children, Adolescents and Their Families*. Chicago, IL: Kaleidoscope.

Stroul, B. A.; Friedman, R. M. 1996. The System of Care Concept and Philosophy. In B. A. Stroul (Ed.), *Children's Mental Health Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co.

States have made progress in promoting evidence-based practices across the age-span.

- ◆ While 50 states (94%) indicated that they promote, require, or support the use of evidence-based practices, only 19 states reported that they promote, require, or support specific evidence-based practices statewide. Currently:
 - Twelve states mandate the use of evidence-based practices, but only eight states with mandates promote, support, or require specific EBPs statewide;
 - Among community stakeholders, community leaders were most likely to have ever heard about evidence-based practices (69%), compared to family members (11%) and youth (7%);
 - Most state mental health advocates (58%) knew about their state's efforts to advance evidence-based practices, but few knew about the specific strategies; and
 - 33% of county and community stakeholders report that a state-sponsored outcomes-based management system propelled implementation of evidence-based practices.

Children's mental health systems have made significant strides in their efforts to be family- and youth-responsive in service delivery and policy, but these efforts may not be enough.

- ◆ Forty-nine state children's mental health directors reported on a range of efforts to strengthen the family and youth voice in policy, but in at least 15 states, mental health advocates reported being dissatisfied with the family and youth voice in policy.

States have implemented policies and strategies to support culturally- and linguistically-competent services and systems, but these appear unsystematic and lack institutionalization.

- ◆ Twenty-seven states reported on policies that promote access to culturally- and linguistically-competent services, but only three states reported that they have implemented a range of purposeful steps to promote cultural and linguistic competence including competency-based training, workforce development, assessment and strategic planning, and stakeholder involvement in policy and programming.

States have mixed records in their efforts to improve service delivery through infrastructure-related supports, fiscal policies and accountability measures.

- ◆ States lag behind in developing the information technology (IT) infrastructure needed to support children's mental health service delivery.
- ◆ Only two states reported advanced information technology infrastructure to support children's mental health service delivery, however 24 states reported intermediate systems, and 19 states described their IT systems as rudimentary.

Accountability and transparency remain major obstacles to furthering strong fiscal structures.

- ◆ Many states remain unable or unwilling to document their child mental health budgets:
 - Twenty-seven states reported on their child mental health budgets;
 - Thirteen states reported that they were unable to report their total budget for children's mental health; and
 - Only 11 states reported funding for children with mental health conditions across child-serving sectors.

Many states have tried to exploit federal and state fiscal opportunities, but barriers persist.

- ◆ The Medicaid rehabilitation option, which permits significant flexibility in funding services and supports, is the Medicaid strategy most often reported by states (N=29).
- ◆ Increasingly states are using Medicaid and state funds to support family members and youth in professional roles in service delivery. Sixteen states reported that they use Medicaid, and 28 states reported that they use state funds to support family members. Twelve states reported that they use Medicaid and 24 states reported that they use state funds to support youth in professional roles.
- ◆ In 28 states, leaders recognized that opportunities exist for reform. They reported implementing innovative fiscal reform strategies such as efforts to expand service capacity, require or promote community reinvestment, braid or blend funding, maximize revenue, and establish practice or performance standards.

Overall, states reported two overarching barriers, fiscal constraints in what could be funded, often linked to Medicaid, and lack of service capacity.

- ◆ States most frequently considered financing (particularly federal Medicaid policy) (N=27), workforce (N=18), and cross-system collaboration (N=16) as the major obstacles to using their systems.
- ◆ Only 19 states reported using Early and Periodic Screening, and Diagnostic Treatment (EPSDT), which allow states to screen, assess, and treat children based on medical necessity, despite its universal availability and applicability.
- ◆ Only 16 states reported that they permit reimbursement to young children for certain services irrespective of whether they have a diagnosis.
- ◆ States reported that not being able to serve children who are at risk of SED but who do not have a diagnosis is a major problem. This gap impacts both young children and school-age children.
- ◆ Even though families tend to trust non-office based settings for services, some states restrict funding for services in non-office based settings, such as child care settings and schools.
 - Ten states reported that they restrict Medicaid reimbursement for mental health services delivered in child care settings and schools, and 14 states restrict reimbursement in parks or recreational settings.
- ◆ For youth in juvenile justice, 23 states reported (based on interpretation of federal law) that they restrict Medicaid reimbursement for mental health services.

States have limited capacity for using outcomes-based decision-making, planning and quality improvement and determining programming and policy effectiveness.

- ◆ Fifteen states rated their capacity for outcomes-based decision-making as rudimentary despite a federal initiative, National Outcomes Measures, designed to focus on outcomes.
- ◆ Forty-five states reported that they had initiatives to improve outcomes management, but it is unclear how deeply rooted these initiatives are or whether they improve service delivery.

- ◆ Forty-one states reported that they make state data and data analysis available for community planning, but 10 state mental health advocates reported that this does not happen in their states.

States identified fiscal barriers as the most critical policy challenge they foresaw to addressing the mental health needs of children, youth, and their families.

- ◆ Twenty states listed state fiscal barriers as a major challenge, and 31 states identified federal fiscal barriers, including Medicaid, among the top policy challenges. States also pointed to challenges with the workforce and the ability to work across systems.

States offered a range of reforms they would like to see implemented to improve children’s mental health service delivery.

- ◆ Twenty-five states reported that they would like to see changes at the federal level related to service delivery capacity. In particular, the federal approach to working with states needs re-tooling, and prevention and early intervention as well as workforce capacity issues need to be addressed. At the state level, children’s mental health directors identified family- and youth-responsive services and cross-systems work as areas where they would like to see changes.

Moving Forward

The majority of states are taking tangible steps to improve their mental health delivery systems for children and youth. While a quick glance at system improvements over the last 25 years suggests a real shift in the culture of care and numerous commendable advancements, particularly stemming from strong state leadership, more in-depth analysis reveals that these changes, while promising, are often limited in scope and depth. The central questions to ask in moving forward are:

- ◆ What should be the vision for a next generation child mental health delivery system?
- ◆ What needs to happen to move us toward that vision?

Based on our study, the next generation child and youth mental health system requires services and supports that range from universal strategies designed to promote mental health and prevent mental health problems, to intervention strategies and aftercare for children and youth with mental health conditions, including those with the most intensive needs. Such a system requires financing, service delivery, and infrastructure-related supports for effective, family-, youth-, culturally-, and linguistically-responsive and research-informed practices.

Characteristics of a Next Generation Mental Health System

- Flexible funding that allows rapid response to emerging knowledge about the development of mental health issues in children and research-informed practice
- Attention beyond children and youth with SED to children and youth at risk of SED through the mental health system
- Dedicated funding for prevention and early intervention
- Increased supports for parenting and for family support services in the context of prevention, early intervention, and treatment
- Implementation of core system of care values
- Incentivized systems to improve quality with specific attention to eliminating disparities based on race/ethnicity, culture, language and age
- Increased workforce capacity and competence, with greater attention to cultural responsiveness
- Use of data to drive clinical and administrative decision-making
- Increased attention to functional outcomes for children and youth
- Integrated delivery systems

Major Recommendations

Congress and the Executive branch should codify into law a public health approach to children's mental health services. Specifically:

- ◆ Provide a legislative framework for incentives and support for states to implement a public health approach for mental health for all children and youth. These incentives and supports can take the form of special grants, a set-aside in current funding streams, and technical assistance;
- ◆ Establish a prevention funding set-aside as part of the mental health block grant mirroring a practice in substance abuse funding and provide training, guidance, and technical assistance to states to implement a public health framework; and
- ◆ Create through legislative authority a requirement for state child mental health authorities, child welfare authorities, and state juvenile courts to work collaboratively with the Substance Abuse and Mental Health Services Administration (SAMHSA), Agency for Children and Families, the Department of Justice, and the Department of Education to develop a comprehensive strategy to address the mental health needs of children, youth, and their families in these systems, with the view to providing increased access to mental health promotion, prevention and treatment interventions.

Make an age- and developmentally-appropriate approach to serving children and youth with or at risk for mental health problems, and their families, a priority. Specifically:

- ◆ Provide incentives for statewide approaches to improving age-appropriate services; and
- ◆ Support states and professional organizations to improve the competencies of all providers (including teachers) who work with children and youth with mental health conditions and those at risk for mental health conditions so they are prepared to meet the needs of children in an age-appropriate manner.

In addition, for young children:

- ◆ Direct the Centers for Medicare and Medicaid Services (CMS) to develop a comprehensive strategy to support the provision of prevention,

early intervention, and treatment services for young children.

For school-age children and youth:

- ◆ Direct the Department of Education and SAMHSA, in conjunction with CMS where applicable, to develop a comprehensive strategy to support the provision of prevention, early intervention, and treatment services for school-age children.

For youth transitioning to adulthood:

- ◆ Remove federal prohibitions that govern federal funding of services to youth in juvenile justice.
- ◆ Make available, at the state option, enhanced federal Medicaid participation rates for all youth with mental health system involvement up to age 25.

Implement a comprehensive plan that finances the delivery of empirically-supported practices through payment structures like Medicaid, private insurance, grants, and incentives. Specifically:

- ◆ Contribute to the financing of more widespread adoption of evidence-based practices in states.

In conjunction with states:

- ◆ Systematically track the use of and outcomes associated with the implementation of evidence-based practice; and
- ◆ Create initiatives that educate youth service users and their family members on evidence-based practices.

Take action to reduce disparities in access to mental health services and mental health outcomes based on race/ethnicity and limited English proficiency. Specifically:

- ◆ Require states to report on their efforts to address disparities in access and outcomes for children and youth from diverse racial, ethnic, and linguistic backgrounds; and
- ◆ Annually report on a state-by-state basis efforts to address disparities through the use of nationally-established benchmarks.

Address the poor information systems capacity of children’s mental health delivery systems and stimulate strategic planning and development. Specifically:

- ◆ Assess the status of children’s mental health information technology infrastructure.
- ◆ Include children as a priority for the national health information technology implementation plan and tap into its capital resources to upgrade these systems.

Develop and implement a comprehensive financing strategy that supports a public health focus to mental health. Specifically:

- ◆ Require child mental health care content expertise in the development of state Medicaid plans and Medicaid policy decision-making;
- ◆ Provide incentives for states to use Medicaid innovatively, such as to support mental health consultation or services in a range of non-office-based settings;
- ◆ Reward states that are using Medicaid and state funding creatively to improve service delivery and tie these rewards to improved outcomes;
- ◆ Identify a set of individual and system-related outcomes for children and youth with mental health conditions and link these to publicly financed public health strategies;
- ◆ Reject federal changes to the rehabilitation option that undermine services in child care, schools, and other settings that children, youth, and their families frequent;
- ◆ Require CMS to ensure that all states maximize the impact of EPSDT on children’s mental health services; and
- ◆ Report on benchmarks for behavioral health screenings and services funded by EPSDT, and establish specific targets for meeting the 80% participation threshold.

Require an outcomes-focused approach to service delivery in children’s mental health. Specifically:

- ◆ Provide incentives and support for states to move toward more outcomes-focused management; and
- ◆ Help states link mental health policy and clinical decision-making initiatives.

State governments, territories, and the District of Columbia should:

- ◆ Support strategic planning to address unmet need in public mental health systems. Specifically,
 - Document periodically and make publicly available estimates of unmet needs across age groups and states’ plans to address these needs.
- ◆ Address racial and ethnic disparities in access to mental health services and in mental health outcomes by:
 - Annually reporting on a county-by-county basis efforts to address disparities through the use of nationally-established benchmarks; and
 - Assessing their state children’s mental health system’s level of cultural and linguistic competence, develop a strategic plan, and publish regular updates of their progress.
- ◆ Create mechanisms to sustain family and youth involvement in practice and policy by:
 - Implementing strategies to support family and youth in professional roles using Medicaid; and
 - Providing long-term funding for family and youth advocacy and support.
- ◆ Attend to the urgent need for updated information systems by:
 - Ensuring that as states develop information systems for other sectors of their child delivery systems they upgrade the child mental health infrastructure for maximum interoperability across child serving systems.
- ◆ Address poor fiscal accountability by:
 - Annually and publicly reporting states’ children’s mental health budgets; and
 - Documenting how states use EPSDT for children and youth with mental health needs and those at risk.

Conclusion

The vast majority of states are taking tangible steps to improve their mental health delivery systems for children. A quick glance at system improvements over the last 25 years suggests a real shift in the culture of care and numerous commendable advancements, particularly stemming from strong state leadership. More in-depth analysis, however, reveals that these changes, while promising, are often severely limited in scope and shallow in depth due to lack of concerted strategic plans.

While the current structure focuses on children with severe mental health conditions, too few resources have been expended to develop a comprehensive framework for addressing the needs of children and youth with or at risk for mental health conditions, and their families. At the same time, efforts to “get ahead of the curve” and implement an approach to service delivery grounded in the public health framework of mental health promotion and prevention of mental health disorders, early intervention, and treatment remain stymied, subject to few if any resources and the good will of a few leaders.

As with *Unclaimed Children* in 1982, we have an opportunity to radically alter the trajectory of children’s mental health policy. Our national and state leaders have the opportunity to take bold policy choices that change how services are delivered. The clear message from this report is that children, youth, and families need their leaders to implement an agenda that places at the forefront the best knowledge about what children and youth need at different stages of their development, effective practices, and the settings and systems most equipped to support them in family- and youth-responsive and culturally and linguistically competent ways.

This framework would put those at risk of mental health conditions on a par with those with mental health conditions. It should drive how services are financed, how training is developed and implemented, how technology is applied, and how the workforce is prepared and compensated, so we can effectively track the outcomes that matter for children, youth, and their families. Now is the time to move forward.



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