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The State of Children's Mental Health in Connecticut: A Brief Overview

Connecticut Voices For Children

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Introduction

The release last year of the Surgeon General's Report on Mental Health² brought renewed national attention to mental health, documenting defining trends in the field (advances in scientific research, new effective treatments, changes in organization and financing of care, and emerging powerful consumer and family movements). It also heightened awareness of the challenges that continue to face the Nation -- in reducing stigma about mental illness, enhancing prevention and treatment, and building a well-coordinated system capable of serving individuals and families across the full life-span.

The work in Connecticut on children's mental health reform, however, began years earlier, and gained momentum with the passage of the landmark legislation, P.A. 97-272. This legislation codified in state law a new community-based "systems of care" approach for children with serious emotional disturbance --a significant departure from Connecticut's tradition of reliance on institution-based care for such children.

Passage of this legislation, however, is widely understood to have been merely the *first recent* step in a quite long and challenging journey.³ The journey,

¹ This summary is part of a longer background report prepared for the Foundation. A special thanks to Pat Baker, the Foundation's Executive Director, to permitting this summary to be more widely disseminated.

² United States Department of Health and Human Services, U.S. Public Health Service, 1999, *Mental Health: A Report of the Surgeon General* [Surgeon General's Report, 1999]

³ Other recent steps in this journey include the release of multiple Child Fatality Review Panel reports by the Office of the Child Advocate on the deaths of children with mental health needs (1998-99), the Legislative Program Review and Investigation's study of the Department of Children and Families (1999), the Department of Social Services' report *Delivering and Financing Children's Behavioral Health Services in Connecticut* (2000) (which focused on children enrolled in the state-sponsored health insurance programs for low-income children -- HUSKY A/Medicaid and HUSKY B/CHIP), and the appointment of a Governor's Blue Ribbon Commission on Mental Health, whose report will be released in July, 2000.

which began with the creation of a consolidated state children's agency in 1975⁴, has as its goal a well-functioning and well-balanced children's mental health system that connects *all* Connecticut children and youth who have mental health problems to *appropriate* care in a *timely* manner, and that also focuses heavily on prevention.

Reform efforts are now accelerating, providing significant hope – for the first time in many years -- for long-desired *true* “systems” reform. Yet, the challenges facing Connecticut in this effort are formidable, providing multiple opportunities for complementary and reinforcing initiatives that can help Connecticut – the state with the nation's highest per capita income – also become the best state in the Nation in children's mental health.

This short state-of-the-state report⁵ highlights some of the challenges that continue to face Connecticut's children's mental health “system” as we enter this new century, and in doing so will identify some of the opportunities for targeted new initiatives that can make an important difference, given current needs and the anticipated recommendations of the forthcoming Governor's Blue Ribbon Commission on Mental Health.⁶

Challenges

A number of inter-related challenges continue to face our state's children's mental health “system.” They include:

1. There *is* no “system” of children's mental health care

Though DCF is designated by state law to be the “lead” agency for children's mental health, in fact there are multiple state agencies⁷ and local school districts all involved in the administration of behavioral health for children and youth. These entities rely for the provision of care on a variety of private and

⁴ The Department of Children and Youth Services (now Department of Children and Families) merged child protective services, children's mental health, juvenile justice, and – some time later -- children's substance abuse services – into a single, autonomous consolidated state agency, the first (and still one of just five) in the Nation. Connecticut Commission to Study the Consolidation of Children's Services, 1975.

⁵ This brief report cannot claim to be exhaustive. A notebook with some key studies and a bibliography accompanies this report to provide greater detail on issues discussed herein, as well as some others not mentioned.

⁶ The author serves as co-chair of one of the Commission's four expert panels and is a member of the Commission.

⁷ They include: Department of Social Services (public financing), Department of Mental Health and Addiction Services (transitioning youth, parent services), Department of Mental Retardation (dually-diagnosed), Department of Education (special education), Judicial Department (juvenile detention), Department of Correction (serious juvenile offenders), Department of Public Health (services for children orphaned by AIDS).

public services (e.g. individual clinicians, child guidance clinics, school-based services, residential treatment facilities, and in-patient child psychiatric facilities).⁸ These services are paid for, in turn, by a variety of sources (e.g. private and public insurance,⁹ state grants, school district special education funds, and private philanthropy). Wholly lacking is a statewide plan that meshes these various services and funding streams into a seamless system, with a single state agency accountable for assuring that the system is well-balanced and well-functioning.¹⁰ The result is a “complex, fragmented system that leaves families confused about where to turn when they recognize their children need help.”¹¹

DCF, with DMHAS, produces each year a *Community Mental Health Plan for Children and Adults* to receive federal Community Mental Health Services block grant funds.¹² While this plan is DCF’s best articulation of a state mental health plan, it is seriously deficient as the template for a coordinated children’s mental health system. It does not include *all* the various state and local entities involved in administering behavioral health services (including the schools), nor private insurers. It does not provide a mechanism to blend funding streams so funding for services can “follow the child” through the continuum of care and ensure that all entities financially responsible for a child’s care actually contribute to that care (rather than cost-shift to others, an increasing problem in the managed care era)¹³. In addition, the plan’s primary focus is on

⁸ DCF alone has more than 300 provider contracts for 23 categories of mental health services, *not* including foster care. CT General Assembly, Legislative Program Review Committee, 1999, *Department of Children and Families* [LPRC, 1999]

⁹ Note that there is significant state and local funding of children’s behavioral health services *independent* of the state’s public insurance program (HUSKY/Medicaid). The February, 2000 DSS study of children enrolled in HUSKY [DSS, 2000] estimated that only 30% of the approximately \$207 million in *public* funds spent for *their* behavioral health care in FY 99 was HUSKY/Medicaid funds, including only \$16.4 million of the \$119.8 million in behavioral health funds DCF spent and only \$8 million of the \$46.8 million spent by the Department of Education and the local school districts. There are no comparable data on the level and types of public *or* private investments in behavioral health services for uninsured children, or for children with private insurance -- the *80%* of the children in the state who are *not* enrolled in HUSKY.

¹⁰ Researchers refer to this collective of care givers, in Connecticut as elsewhere, as the *de facto mental health service system* [Regier et al, 1978], noting that without strong coordination, the system can become organizationally fragmented, creating barriers to access. The *de facto* system includes the specialty mental health sector, the general medical/primary care sector, the human services/school/criminal justice sector, and the voluntary support network sector, all of which depend on multiple funding streams with sometimes competing incentives. Surgeon General’s Report, 1999.

¹¹ DSS, 2000.

¹² Connecticut Department of Children and Families and Department of Mental Health and Addiction Services, *Community Mental Health Services Performance Partnership Block Grant (PPBG) for FY 2000* (including the Community Mental Health Plan for Children and Adults)(for October 1, 1999 to September 30, 2000).

¹³ See Stroul et al, 1998, *The Impact of Managed Care on Mental Health Services for Children and Their Families*. Managed care has demonstrably reduced the cost of mental health services, but

children with more serious mental health needs; less attention is paid to prevention and to the roles of providers who are not mental health specialists. A related challenge is DCF's lack of internal administrative capacity to implement a coordinated statewide plan for children's behavioral health services. Since its creation in 1975, DCF has focused primarily on its protective services¹⁴ and juvenile justice mandates, generally neglecting the co-equal children's behavioral health mandate. Until PA 97-272 established DCF's voluntary services program, parents of children with mental illness or SED who were uninsured or underinsured were forced to commit them to DCF custody to receive intensive mental health services. P.A. 97-272 specified that commitment to DCF cannot be a condition for receiving behavioral health services from the department, established a Probate Court process for reviewing voluntary admissions for behavioral health services, and established a mechanism to appeal the DCF Commissioner's decision to deny a voluntary admission. However, there still are no final regulations for this program (resulting in regional inconsistencies in who is admitted and what services are provided), and as of March, 1999 only 303 children had been accepted (123 receiving out-of-home services and 180 receiving in-home services).¹⁵

Also, while P.A. 97-272 codified the systems of care model for children with SED, the local systems of care are in various stages of development, are inadequately staffed, and lack authority to draw down blended funding for services.¹⁶ In addition, until recently, DCF has had very limited staff within its Central and Regional Offices with responsibility solely for children's behavioral health. The General Assembly's Legislative Program Review and Investigations Committee noted in its 1999 report on DCF that "as a result of its focus on protective services...DCF's management is reactive and crisis-driven. The department does not carry out long range planning or adequately address preventive services." DCF's neglect of its mental health mandate prompted the Committee to propose that all responsibility for children's behavioral health be transferred back to DMHAS.¹⁷

2. The children's mental health "system" is not well-balanced and is in a state of grid-lock

plans differ greatly in access to and quality of care, current financial incentives generally do not encourage an emphasis on quality, and the most severely and persistently ill -- in particular risk -- being under-treated. Surgeon General's Report, 1999.

¹⁴ The 1991 Consent Decree in Juan F. v. O'Neill mandated systems change in all aspects of child protective services. DCF remains under federal court order and is in non-compliance with many aspects of the Decree, resulting in significant continuing attention to its protective service mandate.

¹⁵ LPRC, 1999.

¹⁶ See DCF, 1999, *Report on the Status of Local Systems of Care for Children in Connecticut*.

¹⁷ LPRC, 1999.

Given the lack of a state plan and a single accountable state agency, it is not surprising that the current “system” is not well-balanced. The allocation of funding for services is based in some significant measure on which providers have the greatest political influence, rather than on what services are most needed by children and families. The lack of well-developed state-based parent advocacy organizations, that can provide parents with the tools to advocate for their own children’s care as well as for systems’ reform, has enabled this imbalance to persist.¹⁸

Surveys of Connecticut parents of children with behavioral health needs¹⁹ and other studies²⁰ have shown that the services that are most needed to enable children with mental health problems to remain in their families include day treatment, intensive out-patient services, respite care, wrap-around services and various other community and home-based services.²¹ Yet, a disproportionate, and increasing share, of Connecticut’s public investment in children’s mental health is in institutional care.

For example, the DSS study of the 184,000 children enrolled in HUSKY²² found that of the \$207 million in public funds spent on the 18,216 HUSKY children who needed behavioral health care in 1998-99:

- \$41.1 million (20%) was spent for psychiatric hospitalizations for 1,067 children (5% of children)

¹⁸ See *Focal Point: A National Bulletin on Family Support and Children’s Mental Health*, Fall, 1998 (issue on family participation in policy making); DSS, 2000; Surgeon General’s Report, 1999.

¹⁹ Connecticut Association of Mental Health Clinics for Children, 1998, *The Impact of Medicaid Managed Care on the Delivery of Mental Health Services to Children*; Geballe S et al, 1997, *The Health of Connecticut’s Children’s Mental Health System: Final Report of a Statewide Survey of Families and Providers*.

²⁰ Connecticut Department of Social Services, 2000, *Delivering and Financing Children’s Behavioral Health Services in Connecticut* (and Technical Appendix); National Alliance for the Mentally Ill, 1999, *Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness*.

²¹ Woolston et al, 1998, Intensive, Integrated, In-Home Psychiatric Services, *Child and Adolescent Clinics of North America*, 7(3), 615-633.

²² Medicaid is becoming the “backbone of state mental health systems,” providing coverage for increasing numbers of children and youth. Though Medicaid provides an extremely, comprehensive federally-mandated benefit package for children, the benefits actually provided to them commonly fall short of federal mandates, especially for children with SED under the current managed care model. [Bazelon Center 1999b, 1999c]. Recently, the Children’s Health Council reported serious problems with the duration, intensity, and adequacy of behavioral health services after psychiatric hospitalization for children enrolled in HUSKY A – specifically, high readmission rates (25% of the children were re-admitted within 30 days of discharge) and low rates of ambulatory follow-up care (only 45% received ambulatory follow-up care). [Children’s Health Council 2000]. Qualidigm, DSS’ external quality review organization, also reported deficiencies in EPSDT health assessments for children in HUSKY A: less than half the children were assessed for alcohol, drug, and tobacco use; less than a fifth for depression; and only 38% of males and 59% of females were assessed for level of sexual activity. [Qualidigm 2000]

- \$104.2 million (50%) was spent for residential treatment (including group homes and therapeutic foster homes) for 3,000 children (13%)
- \$61.3 million (30%) was spent for home and community-based services for 18,216 children.

That is, 70% of the funds spent on behavioral health services for children enrolled in HUSKY were spent on institutional placements for 18% of the enrolled children, leaving only 30% of the funds for community and home-based services for the remaining 82% of the children.

A review of DCF's budget over the last several years shows a pattern of rapidly increasing expenditures on residential treatment and only nominal increases in the out-patient and day treatment services that could keep children out of more restrictive and costly placements, as the following table illustrates:

DCF Budget: FY 87-FY 00 (in millions)			
Service	FY 87	FY 98	FY 00*
Grants for psychiatric clinics for children (27 child guidance clinics)	\$6.3	\$10.2	\$11.2
Private day treatment programs	\$1.1	\$4.4	\$5.1
Private residential treatment	\$20.6	\$62.0	\$103.3
Source: Connecticut State Budget.			
Note: FY 00 does not include any deficiency appropriations.			

In addition, DCF's expenditures for behavioral health are disproportionately for children in the agency's custody. In FY 99, DCF spent about \$91 million (76%) of its total behavioral health budget on children committed to state custody through protective services or juvenile justice, about \$11.5 million for children in DCF's voluntary services program, and the balance of \$18 million for services used by children in the community without formal DCF involvement.²³

Gridlock. DSS' recent report on HUSKY behavioral health care emphasizes the importance of shifting focus from costly and often unnecessary residential²⁴ and hospital care toward a more flexible funding model that supports the intensive clinical and non-clinical support services necessary to keep children with SED home. Such fundamental systems change is necessary to end the

²³ LPRC, 1999.

²⁴ Nationally, about one-fourth of children's mental health dollars are spent on residential care for about 8% of treated children [Burns et al, 1998], compared to -- in Connecticut for children enrolled in HUSKY -- 50% of total mental health dollars for 13% of the treated children. [DSS, 2000]

pervasive grid-lock that now exists in our state's children's mental health system.

Increasing numbers of children with acute psychiatric needs are being cared for in hospital emergency rooms and general pediatric wards due to a reduction in the total number of in-patient beds for children,²⁵ and the fact that many children's in-patient beds are filled with patients ready for discharge who need less restrictive placements that are in too short supply.²⁶ In turn, residential treatment facilities are at or near capacity, yet many children in residential care who no longer need of *this* level of care cannot be discharged home because there are insufficient community and home-based services to support their return.

This gridlock is harmful clinically for the children "stuck" in inappropriate placements and unnecessarily costly.²⁷ It is also contrary to the recent United States Supreme Court decision in Olmstead v. L.S., 119 S. Ct. 2176 (1999). This decision establishes that states have a legal obligation under the Americans with Disabilities Act to assure that persons with disabilities (which include mental disabilities) are able to live in the most integrated setting appropriate to their needs.²⁸ Connecticut's failure to invest adequately in

²⁵ Riverview Hospital in Middletown, a JCAHO-accredited 98-bed facility, is the only state-administered psychiatric hospital for children under 18 and primarily serves children in DCF custody. It consistently runs a waiting list that averages 20 children per day. Since the late 1980s, DCF has reduced by 51 the number of DCF-operated treatment beds, closing the Altobello and Housatonic Hospitals (a total of 92 beds for youth) while increasing the capacity at Riverview by only 41 beds. DCF operates two other residential facilities -- High Meadows (42 youth beds) and Connecticut Children's Place (54 youth beds) but they primarily serve children in protective services with less acute need. Currently, there are at least 10 private Connecticut psychiatric or general hospitals with beds for children and youth that serve, as of late March 2000, about 87 DCF children (and an additional number of non-DCF children). DCF reports that since 1995, 64 private child and adolescent beds have closed.

²⁶ DCF's monthly Sub-Acute Hospital Status reports document that as many as half of Connecticut's private in-patient psychiatric beds occupied by children in DCF custody are for children in sub-acute status who are awaiting discharge to a more appropriate placement. The Judicial Department also reports that each day about 30% of the youth in the state's the three juvenile detention centers are awaiting residential placement. The placement process takes 6-8 weeks on average, and can take months if the child has special treatment needs (such as severe psychiatric illness or mental retardation). State of CT, Judicial Branch, 1999, *Comprehensive Report on Juvenile Detention in Connecticut*.

²⁷ Connecticut spent, for example, \$16.5 million in reinsurance between September, 1998 and February, 2000 to assure that children no longer in need of in-patient hospital care could remain in the hospital until a less restrictive placement could be identified. DSS, 2000; Children's Health Council, 2000 (conversation with Judith Solomon, Executive Director)

²⁸ Bazelon Center for Mental Health Law, 1999, *The Supreme Court Ruling in Olmstead v. L.C.*; United States Department of Health and Human Services, Health Care Financing Administration, *Letter to State Medicaid Directors on Olmstead v. L.C.* (January 14, 2000). Failure to create a continuum of services that assures children are cared for in least restrictive settings could also violate federal and state constitutional due process guarantees, as well as the state constitution's prohibition on segregation and discrimination based on disability.

community-based behavioral health services for children, resulting in increased out-of-home (and even out-of-state) placements²⁹ and system “gridlock,” is contrary to the ruling in Olmstead.³⁰

Also, notably absent from Connecticut’s children’s mental health “system” are well-defined, well-articulated, and adequately-funded prevention services. As the General Assembly’s Legislative Program Review and Investigations Committee noted, DCF’s “actual role in funding and operating primary prevention programs for children and families...is relatively small.”³¹ Also limited is DCF, or *any other* state agency’s, work in secondary and tertiary prevention.³² In addition, the primary current focus of legislative, executive, and community attention in children’s mental health in Connecticut is on the care of children with serious emotional disturbance, and – in particular – children with SED who are enrolled in HUSKY. This focus is not surprising, as these children are the state’s high-cost users. Yet, without equal attention paid to primary, secondary and tertiary prevention for *all* children, the state can be virtually assured that the number of children in need of the state’s “highest end” services will continue to climb.

3. Demand for services will likely increase

National studies show that in any given year about 20% of children have mental disorders with at least mild functional impairment.³³ A subset of these children and youth (up to 9% of children ages 9-17 for example) have *significant* functional impairment, known as “serious emotional disturbance” (SED) while about 5% have *extreme* functional impairment.³⁴ This suggests that about 157,000 Connecticut children and youth out of a total population of

²⁹ In FY 00, there were 470 *more* children in residential treatment, group homes and shelters than in FY 94, an increase of more than 40% (from 1,164 to 1,635). Over the same period, the number of children in foster care more than doubled (from 1,737 to 4,100). CT State Budget, 1995-7, 1997-9, 1999-01.

³⁰ The Department of Social Services, building on the work of its Long Term Care Planning Committee, is developing a comprehensive state plan to respond to Olmstead.

³¹ DCF’s total expenditures on its prevention mandate are about \$5.3 million. Two-thirds of this is through the Children’s Trust Fund which is within DCF for administrative purposes only, and is overseen by an independent Council on which the DCF Commissioner sits as one of 16 members. LPRC, 1999.

³² As used in this report, primary prevention is defined as protecting health and preventing the incidence of illness. Secondary prevention reduces the prevalence of illness in a population by early detection and intervention to prevent recurrence or exacerbation of illness that has been identified. Tertiary prevention reduces the amount of disability caused by an illness to achieve the highest level of functioning. Last JM, 1988, *A Dictionary of Epidemiology* (2d ed.); Surgeon General’s Report, 2000.

³³ These disorders include mood disorders (e.g. depression and bipolar disorder), anxiety disorders (e.g., panic, post-traumatic stress), adjustment disorders, pervasive developmental disorders (e.g. autism) and psychotic disorders (e.g. schizophrenia).

³⁴ Surgeon General’s Report, 1999.

786,000 children currently have mental disorders. Of these, about 71,000 have SED and about 39,000 are *extremely* functionally impaired.

Connecticut studies suggest that the prevalence of mental health problems among Connecticut children are at least equal to, and may exceed, national averages.

The CT Department of Public Health's *Voice of Connecticut Youth* study (1997), a statewide survey of 12,000 7th, 9th, and 11th graders, found that one-third of the youth reported that they had serious emotional or mental health problems in the preceding year (compared to between one in five and one in four youth nationally, according to the report's authors).³⁵ Twelve percent of 7th grade girls, 14% of 9th grade girls, and 8% of 11th grade girls reported that they had attempted suicide once or more in last year; twice the male rate. The Center for Disease Control and Prevention's (CDC) 1999 Youth Risk Behavior Surveillance Study found that 8% of Connecticut high school students reported they attempted suicide in the past year, down from 9% in the 1997 survey and comparable to the national average.³⁶ Alcohol use is also comparable: 50% of Connecticut high school students report drinking alcohol in the last month, and 28% report episodic heavy drinking (defined as five or more drinks at a time once or more in the last month).

Four general trends suggest that the demand for children's mental health services will likely *increase* in Connecticut.

First, a number of the factors associated with increased risk of mental health problems among children³⁷ have themselves increased. For example, between 1985 and 1996 in Connecticut:

- **child poverty**³⁸ (family income of \$16,700 or less for a family of four) increased from 12% to 17%, though the state's rank as highest in per

³⁵ Beuhring T et al, 1997, *Voice of Connecticut Youth: Interpretive Report of Educational Unified School District II* (CT Department of Public Health).

³⁶ Centers for Disease Control and Prevention, 2000, Youth Risk Behavior Surveillance- United States, 1999, *MMWR* 49, No. SS-5 (June 9, 2000)

³⁷ As the Surgeon General's Report on Mental Health notes, "Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors." (p. 193) These factors include: prenatal damage from exposure to alcohol and other harmful substances; low birth weight; family history of mental and addictive disorders; biological abnormalities caused by injury, infection, poor nutrition, or exposure to toxins (like lead); intellectual disabilities (retardation); and external risk factors such as poverty, caregiver separation or abuse and neglect, parental behavioral health disorder, or exposure to traumatic events.

³⁸ Low socioeconomic status (in terms of income, education, and occupation) has been strongly linked to mental illness; persons who are in the lowest socioeconomic strata are about two and a half

capita income did not change and child poverty *declined* nationally over this period. In 1989, when our economy was last very strong, Connecticut's child poverty rate was only 7%.

- **births at low birth weight** increased from 6.6% of all births to 7.2%.
- **families headed by a single parent** increased from 22% of all families with children to 27%. While some of this increase is attributed to divorce, other causes of caregiver separation also are increasing in Connecticut, including parental death due to HIV/AIDS and parental incarceration (which disproportionately affects children of color).

In addition, child abuse and neglect reports have more than doubled since 1990 and quadrupled since 1970. Nearly 8 in 10 substantiated reports involve children under 10 years of age and 36% involved physical or sexual abuse. Connecticut's rate of child maltreatment is now 6th highest in the nation, at 21.4 victims per 1,000 children.³⁹

The significance of this increase is clear. CT Voices for Children's secondary analysis of the *Voice of Connecticut Youth* data found that, compared to children who reported no abuse, abused children were: six times more likely to have attempted suicide, five times more likely to carry weapons, and twice as likely to get into fights, have trouble with the police, skip school, use drugs, and perform below average in school. Also, despite an overall decline in crime in Connecticut, domestic violence has been increasing.⁴⁰ *Witnessed* violence also poses risk to children.

The second trend suggesting that demand will increase for children's mental health services is the markedly increased attention being given to mental health, and concurrent efforts to promote public understanding of treatment advance, to reduce stigma, and to reduce access barriers. Since approximately half of children and adolescents with a diagnosable mental disorder currently receive *no* treatment in any sector of the health care system, these efforts may result in greater demand as care-seeking increases.⁴¹

times more likely than those in the highest strata to have a mental disorder. Holzer et al, 1986; Regier et al, 1993.

³⁹ United States Department of Health and Human Services, 2000, *Child Victims of Maltreatment*. Nationally, 54% of the maltreated children were neglected, 23% suffered physical abuse, and nearly 12% were sexually abused.

⁴⁰ From 1997 to 1998, there was a 6.3% increase in family violence leading to arrests, or a total of 19,830 arrests (all time high according to the Connecticut Department of Public Safety).

⁴¹ Shaffer et al, 1996. Shaffer also found that of the 21% of children and youth who receive any mental health services in a year, about 10% had a diagnosable disorder, while more than 11% received care for mental health problems that did not fully meet diagnostic criteria. In addition, nearly 11% of the 21% of children and youth who received mental health care received it exclusively from the schools or the human services sector, 1% from general medical providers, 1% from child welfare and juvenile justice professionals, and only 8% from mental health specialists.

A third trend leading to greater demand for services is increasing racial and ethnic diversity among Connecticut children and youth. Although the total number of children under age 18 in the state is expected to *fall* by 2% between 1997 and 2005 (from 792,200 to 776,500), the number of African-American children is projected to increase by 12% (from 85,800 to 96,500) and the number of Hispanic children to increase by 21% (from 94,200 to 113,900).⁴² By 2010, more than 1/3 of Connecticut's school children will be African-American, Latino, Asian or another minority.

The unfortunate close association in Connecticut between race/ethnicity and poverty and certain other risk factors for mental disorders suggests that as the proportion of African-American and Hispanic children in the state increases, so too will the demand for mental health services in general, and for culturally-relevant and culturally-competent services in particular. As the Surgeon General's Report on Mental Health notes, "The U.S. mental health system is not well equipped to meet the needs for racial and ethnic minority populations....Without culturally competent services, the failure to serve racial and ethnic minority groups adequately is expected to worsen, given the huge demographic growth in these populations predicted over the next decades." (p. 80)

Finally, until the state makes a greater investment in all levels of prevention, Connecticut can anticipate that the demand for *intensive* services will continue to climb.⁴³ For example, the number of children placed in residential care by DCF has increased from 890 in FY 94 to 1,268 in FY 99. Most of these children are older adolescents with very difficult behaviors to manage and treat. An increasingly large subset of these youth are particularly difficult to place (because of assaultive, suicidal, and/or sexual offending behaviors, mental retardation, or specific physical challenges) and are being placed out of state (348 children in December, 1999, representing 27% of all DCF placements and a 40% increase in three years).

⁴² Annie E. Casey Foundation, 1999, *Kids Count Databook*

⁴³ The Office of the Child Advocate's Child Fatality report on Tabatha B. graphically illustrates this point, documenting how multiple missed opportunities for early intervention ended in the suicide death of this 15-year old at Long Lane in 1998. Born to a single mother with significant mental health problems, Tabatha was physically abused from 2 weeks of age, and also later sexually abused and chronically neglected. Placed in multiple foster homes, she attempted suicide at the age of five, and though termination of parental rights was recommended at that time, no such action was taken until she was 13. By the age of 15 she had been the victim of physical assault, had been raped, and had periodically threatened suicide. Her multiple placements in foster and residential care continued, until she was committed also as a delinquent and transferred to Long Lane for assaulting a staff member in a residential facility. The report noted, "Tabatha did not receive the proper care and treatment necessary to address her need for permanence and her mental health issues.... As a consequence, Tabatha moved from one end of a continuum where she once had been regarded as a deserving victim to the opposite end where she was viewed as an undeserving delinquent."

Youth with serious mental health problems present particular challenge as they “age out” of the children’s system.⁴⁴ The normal developmental challenges of starting to live independently, difficult enough for all teens, can be insurmountable for these youth, who are far less likely than their peers to complete school and far more likely to end up in prisons, psychiatric hospitals, or homeless. Recently, a partnership has been forged between DCF and DMHAS to help youth with mental health problems in this time of major transition.⁴⁵

4. The “invisible” issues

The challenge of establishing and maintaining a well-functioning children’s mental health system that includes a full continuum of services -- from primary prevention through in-patient care -- is not new to Connecticut. Review of three decades of reports written about children’s behavioral health in Connecticut reveals striking consistency in articulated goals, and also remarkable consistency in the descriptions of the difficulties attaining them. What is also remarkable, however, is how certain important issues have failed to gain the attention they merit in this 30-year dialogue. This list, which is far from exhaustive but begins to define the areas of unique opportunity, includes:

a. The mental health needs of at-risk children and the role of prevention

Preventing an illness from occurring is inherently better than having to treat the illness after its onset.

Surgeon General’s Report on Mental Health, p. 62

The relationship between stressful life events and risk for child mental disorders is well established. For example, parental death or divorce poses a risk for onset of major depression in young children. The suicidal death of a relative or friend creates risk for youth suicidal behavior and other dysphoric states.⁴⁶ Physical abuse of a child is associated with insecure attachment, psychiatric disorders such as post-traumatic stress disorder, conduct disorder

⁴⁴ See Breetz, 2000; Breetz & Brown, 1997. DCF projects that 45-50 children in its custody are in need of DMHAS transition services in any given month, while others will not meet the eligibility requirements for DMHAS services, which are narrower than DCF’s, and will risk homelessness and criminal justice involvement.

⁴⁵ DMHAS/DCF Interagency Agreement, *Client Transition from the Department of Children and Families to the Department of Mental Health and Addiction Services*. This collaboration involves special programs with developmentally-appropriate services for young adults who are “aging out” of DCF and require continued mental health care from DMHAS (the Transitional Services Project), as well as a Special Populations Program that provides care to young adults with a diagnosis of Pervasive Developmental Disorder (PDD) and/or sexual acting-out behaviors such as pedophilia.

⁴⁶ Garmezy, 1983; Garber & Hilsman, 1992; Gruendel, Geballe, & Andiman, 1995; Clark & Goebel, 1996.

and depression, while psychological maltreatment is associated with depression, conduct disorder and delinquency and can impair children's social and cognitive functioning.⁴⁷ Exposure to acts of violence also places children at risk for stress-related mental health problems.⁴⁸

In addition, the work of John Bowlby and others establishes that instability in a child's caregiving relationship - whether because of physical distance, erratic patterns of parental behavior, parental depression or substance abuse,⁴⁹ or even physical or emotional abuse - can interfere with a child's sense of trust and security, potentially giving rise to anxiety and mental health problems such as depression later in childhood, or even decades later in life.⁵⁰

While most children are inherently resilient and can deal with some degree of adversity, children with inherent biological vulnerability are more likely to be harmed by an adverse environment -- and when stressful life events are long-standing, repeated, or multiple in number, a mental disorder is likely to be induced in all but the hardiest of children.⁵¹ Mental health and mental illness are not discrete categories, but points on a continuum. For any given child, at any given age, movement is possible along that continuum -- in either direction.

Research provides increased understanding of the identity and nature of the risks to healthy child development, the importance of age and timing in a child's vulnerability to risk, potential targets for intervention, and the windows of opportunity during a child's development when preventive or treatment interventions may be especially effective. Research also establishes the essential role that protective factors⁵² can play in averting the development of a mental disorder in a child, or helping a child's recovery.

As explained in the Surgeon General's Report, "Prevention researchers use risk factors to identify populations for intervention, and then they target risk factors that are thought to be causal and malleable and target protective

⁴⁷ Surgeon General's Report, 1999 (and references cited therein).

⁴⁸ Jenkins & Bell, 1997. The Yale/New Haven Child Oriented Community Policing Program addresses this issue head on, with the Child Study Center providing training to police officers on the mental health needs of children exposed to violence and using teams of police and mental health specialists to respond to situations in which children have witnessed or been the victim of violence. It has become a national model. Marens S & Berkman M, 1997.

⁴⁹ Approximately one in four children under the age of 18 in the United States is exposed to alcohol abuse or alcohol dependence in the family. Grant, 2000. About 11% of all children live in households in which at least one parent is an alcoholic or in need of substance abuse treatment. US Department of Health & Human Services, 1999. A 1997 Connecticut study, *Substance Abuse Treatment Needs of DCF Committed Youth in Placement*, found that 67% of the youth reported having a family member with who had alcohol problems and 72% had a family member who used marijuana or cocaine. DCF/DMHAS, 2000, Community Mental Health Services Block Grant.

⁵⁰ Bowlby, 1951; Bowlby, 1969; Rutter, 1995.

⁵¹ Surgeon General's Report, 1999.

⁵² Protective factors improve a person's response to some environmental hazard resulting in an adaptive outcome.

factors that are to be enhanced. If the interventions are successful, the amount of risk decreases, protective factors increase, and the likelihood of onset of the potential problem also decreases....Many mental health problems, especially in childhood, share some of the same risk factors for initial onset, so targeting those risk factors can result in positive outcomes in multiple areas.” (p. 64)

In addition, the concept of accumulation of risks in pathways that accentuate other risks has led prevention researchers to the concept of ‘breaking the chain at its weakest links’” – that is, changing the risks that are most easily and quickly amenable to intervention. These prevention interventions can reduce the impact of the challenges to a child’s development that may lead to mental disorders and also redirect a child whose development already has begun to go awry.⁵³

Such well-targeted, focused interventions, however, are not routinely provided to promote the mental health of at-risk children and youth. Rather interventions commonly occur only when children begin to show signs of a mental disorder, and health insurance tends to cover only the care necessary to stabilize a crisis.

b. The mental health needs of children in the child protective service and juvenile justice systems

Children in [state] care have no continuous adult advocate and alone carry the burden of efforts made by even well meaning adults.

Juan F. v. O’Neill Report on Mental Health (1990)

A related inadequately-addressed issue concerns children in state custody. A primary motivation for the creation of DCF was an acute awareness of the mental health needs of children of children in protective services and juvenile justice.⁵⁴ The 1974 Report of the Commission to Study the Consolidation of

⁵³ The Surgeon General’s Report describes what it considers to be several exemplary interventions that focus on enhancing mental health and primary prevention of behavior problems and mental health disorders among at-risk children. Programs include: Project Head Start, the Carolina Abecedrian Project (infancy to age 8), the Infant Health and Development Program, the Elmira Prenatal/Early Infancy Program, the Primary Mental Health Project (primary school-based), and FastTrack (school and home-based). (pp. 133-136)

⁵⁴ Among youth at Long Lane, more than 70% of girls and nearly 20% of boys have a history of parental abuse or neglect, more than half the girls and nearly 20% of boys exhibit suicidal behaviors, 85% of girls and 71% of boys abuse alcohol and/or drugs, and 36% of girls and 29% of boys are grieving a significant loss (such as the death of a loved one to violence or disease). One-quarter to one-third of the youth receive treatment with psychotropic medication at some point in their stay. Average census in 1998 was nearly 240 youth (up from 152 a year earlier) in a facility with a capacity of 176. DCF, Long Lane School Today, 1999.

Children’s Services noted: “Too often in the past a child might start off needing something like Long Lane, develop evidence of mental disorder and need a mental institution, and then, still later, long term care in a foster home. To obtain these three kinds of services required extensive negotiations among three different state departments. The expectation of the proposed organizational structure is to avoid this and consider the best interests of the children, not of the departments.” (p.22)

For decades, however, the full promise of this single state agency has been unfulfilled. While a highly publicized suicide⁵⁵ and federal litigation⁵⁶ have drawn attention to the mental health needs of youth in the juvenile justice system,⁵⁷ and resulted in some enhancements in mental health care, far more is required. In addition, abused and neglected children in DCF custody – who are at enormous risk not only because of parental maltreatment but because of the likelihood of multiple foster care placements -- do not routinely receive mental health care to help them cope with their history of trauma and multiple loss. Rather, care is provided primarily at times of crisis.⁵⁸ And while all professional staff working in juvenile justice and protective services should view their responsibilities as including the promotion of the mental health of the very at-risk children in their care, their training does not adequately prepare them for this task, and they may perceive their roles quite differently – punishing youthful offenders and protecting the safety of children who are abused or neglected.

c. The essential role of schools⁵⁹

⁵⁵ After the Office of Child Advocate’s report on the suicide death of a 15-year-old at Long Lane, DCF added additional mental health coverage at Long Lane, created a special mental health unit, and revised various policies and practices to respond in a more appropriate manner to the needs of confined children with mental health needs.

⁵⁶ To comply with the federal court order in Emily J. v. Weicker, the Judicial Department: increased mental health coverage from 18 hours to 36 hours/week/juvenile detention center; implemented a health education curriculum for detainees that includes training in anger management and substance abuse; purchased specialized beds to deter suicide attempts; trained selected intake staff to identify potential mental health problems among detainees and implemented a suicide prevention plan; and collaborated with DCF to establish a 12-bed forensic psychiatric unit at Riverview Hospital for delinquent juveniles.

⁵⁷ Most youth in the juvenile justice system have at least one diagnosable mental health disorder, at least one in every five youth has a serious mental health problem, and many of the youth with mental illness have a co-occurring substance abuse disorder. Otto et al, 1992.

⁵⁸ The federal Consent Decree in Juan F. v. O’Neill mandated a series of enhancements in mental health care for children in protective services, including multi-disciplinary assessments, Regional Resource Groups to provide clinical backup to protective services workers, and expanded community-based services. DCF, however, has not fully complied with the mandates of this Decree. See DCF Court Monitor’s Office, 2000, Juan F. Consent Decree Status Report.

⁵⁹ In this context, “schools” includes not only K-12 educational programs, but also preschool programs and post-secondary education programs.

After the family, schools have perhaps the greatest influence on the development of children, so are necessary players in all efforts to promote mental health and provide mental health services. Schools are uniquely positioned to provide behavioral health education to children and youth and to act as points for early identification of youth with mental health needs.⁶⁰ Schools also are increasingly important direct providers of mental health care. According to the Surgeon General's Report, fully half of the mental health services provided to children and youth are through schools.⁶¹

In addition, schools can play a critical role in creating learning environments for children and youth that reduce stigma and prejudice, are emotionally-supportive and respectful of diversity, and help students learn skills to manage conflict and cope with stress. Yet, behavioral health education – with training in such topics as social-emotional learning, early identification of children with mental health problems, suicide and substance abuse prevention, and conflict resolution and peer mediation techniques -- is not a required course in the teacher or school administrator certification process, nor is it required as part of their continuing education.

In short, schools remain far less than full partners in this work. In fact, in much of the current state dialogue about reform of Connecticut's children's mental health "system" the schools are not even full participants. For example, the recommendations for blended funding made in DSS' 2000 report on delivering and financing children's behavioral health services excludes the schools' special education funding from the mix⁶² and there are few representatives from the State Department of Education, local school districts, or education organizations on the Governor's Blue Ribbon Commission on Mental Health and its four expert panels.

⁶⁰ Poduska JM & Kendziora K, Mental health screening and services in the schools: A public health approach. *Focal Point* (Fall 1999).

⁶¹ In addition, the education system is a major funder of residential services for children with behavioral health needs, through its special education mandate. Of the 6,897 Connecticut children aged 3 to 21 who received out-of-district residential placements in the 1998-99 school year, 47% (3,242 children) required behavioral health services. Only 423 of these 3,242 children (13%) were enrolled in HUSKY, yet the cost of placing just these children was \$14.53 million, or more than \$34,000 per child. DSS, 2000, Technical Appendix. Because federal and state law makes local school districts liable for special education costs, and because there currently is no pooled funding across legally-liable agencies, schools may be cautious about identifying children's mental health needs, fearing that large special education costs may result.

⁶² The Surgeon General's Report cautions that managing only the Medicaid portion of a complex funding system that includes Medicaid, mental health, special education, child welfare, and juvenile justice funds "not only creates...cost-shifting...but also underestimates the need to manage the funds spent by all agencies." A preferred model is the creation of an interagency funding pool, shared by *all* affected agencies with funds in the pool capitated to ensure that "the most appropriate services are purchased, regardless of which agency's mandate they come under." [Surgeon General's Report, 1999, p. 185]

d. Racial and ethnic disparity in access to and types of mental health services

While no data conclusively show that there are differences in access to care and the type of care a Connecticut child receives that are associated with the child's race or ethnicity, available data exist suggest that such disparities may exist.

A number of studies (including one from Connecticut and two from New York) have sought to determine why youth with certain levels of acting-out behaviors, substance abuse, and/or psychiatric diagnoses are placed in psychiatric facilities while other youth with comparable problems are remanded instead to juvenile correctional facilities. These studies suggest that the race of the youth strongly influences placement, with disproportion numbers of African-American youth being admitted to correctional facilities.⁶³

Recent Connecticut data appear to corroborate this. The 2000 DSS study on HUSKY behavioral health service found that among the children placed in residential treatment through DCF, minorities were disproportionately under-represented if compared to HUSKY A demographics (though over-represented compared to the state's general population). Specifically, while 62% of the children enrolled in HUSKY are African-American or Latino, only 46% of the residential placements by DCF in 1995 were of African-American or Latino children. (Overall, 23% of the state's children are African-American or Latino.) On the other hand, approximately 70% of the youth admitted to juvenile detention are African-American or Latino (a proportion that has increased over the past decade)⁶⁴ and an increasing proportion of these youth have serious emotional and behavioral problems.

Research is needed to identify whether such disparities exist, and – if they do – why they do and what can be done to remedy the differing treatment.

e. Co-occurring disorders

Recent research documents the high prevalence of co-occurring substance abuse disorders among persons with mental health disorders. In fact, about half of all adolescents receiving mental health services in the general population are reported as having a dual diagnosis, while the rate among

⁶³ See the 1998 Report of the Office of the Child Advocate on the Death of Tabatha B, and studies cited therein.

⁶⁴ Judicial Branch, 1999. The average daily population at Connecticut's three juvenile detention centers has increased from 72 to 126 since 1989, due both to increased admissions and increased length of stay.

youth in the juvenile justice population is likely higher.⁶⁵ DCF reports that about two-thirds of the children in out-of-home placement reported using alcohol or marijuana in the past year and nearly 30% of children in placement have a substance abuse problem.⁶⁶ In the past year, DCF added a full-time substance abuse counselor to provide care to substance-abusing youth at High Meadows and Connecticut's Children's Place.

The Governor's Blue Ribbon Task Force on Substance Abuse (1996) highlighted increasing substance abuse among Connecticut youth as one area of the state's system of prevention and treatment that needed improvement. It recommended (among other things) early intervention services targeted to children and youth at risk for substance abuse (including the estimated 160,000 youth living with a parent currently receiving substance abuse treatment services, and youth with a mental health problem) and a statewide social marketing plan to change alcohol and drug-taking behaviors.

The Governor's Blue Ribbon Task Force on Mental Health has identified co-occurring disorders as an issue in the *adult* criminal justice system. Yet, it is unclear if *youth* with co-occurring disorders will also be the focus of recommendations. Also, as is true in children's mental health, multiple agencies play a role in youth substance abuse prevention and treatment work (with DCF the "lead" state agency), and there is similar fragmentation. To date, there is no coordinated plan for serving youth with co-occurring mental and substance abuse disorders, and for targeted interventions to reduce the prevalence of such disorders.

A second area of concern – also not well addressed -- is the care of children who are dually-diagnosed with mental retardation and behavioral health needs. In particular, it is hard to secure appropriate services for children whose level of retardation is not severe enough to qualify them for services through DMR.

f. The challenges of assuring care for uninsured or underinsured children with mental health needs

Though recent expansions in HUSKY eligibility have reduced the number of uninsured children in Connecticut, significant numbers of children remain uninsured. In addition, some children who *have* health insurance find that they are *underinsured* when they develop a mental health problem that is severe and/or persistent, since many commercial policies set limits on the amount, duration or scope of care allowed, or require co-payments the family cannot afford.

⁶⁵ Greenbaum et al, 1996; Otto et al, 1992.

⁶⁶ Connecticut State Budget 1999-2001.

According to the Surgeon General's report, "Concerns about the cost of care – concerns made worse by the disparity in insurance coverage for mental disorders in contrast to other illnesses – are among the foremost reasons why people do not seek needed mental health care." (p. 23) One study found that lack of parity for mental health care meant that a family with mental health treatment expenses of \$35,000/year had an out-of-pocket burden of \$12,000, while a family with \$60,000/year in treatment expenses paid \$27,000 out-of-pocket. This was far higher than the out-of-pocket expense of only \$1,500 and \$1,800, respectively, that a family would have to pay for medical/surgical treatment.⁶⁷ A recent GAO report⁶⁸ found that new federal⁶⁹ and state⁷⁰ standards requiring some parity between coverage for the treatment of mental health illness and that of other illnesses has had little effect on access to mental health services, in part because employers have reduced mental health benefits to offset the required enhancements

For children with severe disorders, the challenges to receiving necessary care may be particularly high in the current era of managed care. As the Surgeon General's report notes: "In light of cost-containment strategies of managed care, concerns about under-treatment still are warranted for individuals with the most severe disorders, but high quality managed care has the potential to effectively match services to patient needs." (p. 458).

DCF's "voluntary services" program was established to help assure that *all* children with serious mental health needs have access to care – it is the "safety" net for uninsured and underinsured children with severe need. However, DCF often gives preference to "its" children – that is, children in DCF custody – in the competition over scarce in-patient and residential beds and other DCF-funded mental health services. Thus, parents may feel pressured to commit their children to DCF custody to secure care.

Summary

Mental illness (including suicide) ranks second to cardiovascular disease in lost years of healthy life in established market economies like the United States. It

⁶⁷ Zuvekas S et al, 1998, Mental health parity: What are the gaps in coverage?, *Journal of Mental Health Policy and Economics*, 1, 135-146.

⁶⁸ United States General Accounting Office, 2000, *Mental Health Parity Act: Despite New Federal Standards, Mental Health Benefits Remain Limited*.

⁶⁹ The federal Mental Health Parity Act of 1996 requires parity only in annual and lifetime dollar limits, and does not place restrictions on other plan features, such as hospital and office visit limits.

⁷⁰ Connecticut's mental health parity law [PA 97-8, Special Session; PA 99-284, Special Session] is one of the most progressive in the nation, requiring parity in benefits for in-patient hospitalization, outpatient services, cost-sharing, and annual and lifetime dollar limits and applying to virtually all mental and substance abuse disorders. However, it applies to only "non-ERISA" plans, which affect about 50% of all state residents covered by employer-based health insurance. Also, the extent of compliance with this parity requirement is not known.

imposes enormous emotional cost on children and their families and also results in substantial societal costs, in reduced or lost productivity and in resources used for care, treatment and rehabilitation (direct costs). There is strong and growing momentum within the state to improve the children's mental health system. Private investments, joined with new public investments, will assure that this occurs.

The challenges outlined above present a plethora of opportunity. This report is but a point of departure for continued exploration and partnership among those interested in children's mental health to seize these opportunities and make Connecticut's children's mental health system the best in the Nation.

One thing is clear, however:

The significant problems we face cannot be solved at the same level of thinking we were at when we created them.

Albert Einstein

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