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BEYOND SYSTEMS OF CARE FOR CHILDREN AND ADOLESCENTS?

By
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Although frustrated efforts to build collaborative systems go back to Biblical times (think Tower of Babel), the specific form of collaboration known as "system of care for children and adolescents with serious emotional disturbance" (SOC) goes back only about 35 years. It has been at the heart of child mental health policy in the United States ever since.

But recently, and especially since the passage of the Affordable Care Act (ACA), ambitious new goals for child mental health have emerged, emphasizing hopes to prevent emotional disturbance and to serve all children and adolescents with emotional struggles, not just those whose functioning is already quite limited.

Have these ambitious new undertakings made SOC largely irrelevant? Would it matter if it were displaced?

I am not at all sure what the answers are. On the one hand, SOC rests on important values that need to be preserved. On the other hand, even after 35 years, systems of care do not exist or exist only partially in most localities in the United States. Perhaps the goal of service integration will be more broadly achieved through new managed care structures that are now being planned.

Perhaps, but the new ideas are untested, and what we can imagine is always better than what we can achieve in reality. We will have to see what unfolds.

Background:

The concept of systems of care for children and adolescents goes back to 1982 when Jane Knitzer published *Unclaimed Children.*[1] She maintained that a significant majority of children and adolescents with serious emotional disturbance do not get the treatment they need and that the care they get is dysfunctionally fragmented among various child serving systems, including mental health, education, child welfare, juvenile justice, pediatrics,

developmental disabilities, and more. The solution—build local systems of care that bring together the various child-serving systems to work cooperatively to help children and adolescents with serious emotional disturbance and their families.

The idea caught on quickly. In 1983, the National Institute of Mental Health began the Child and Adolescent Service System Program (CAASP). In 1984 Congress provided a bit of funding. In 1986, the federal Comprehensive Mental Health Services Plan Act called for integrated services for children with serious emotional disturbances through the development of systems of care. In 1992 the same act that created SAMHSA established a Children's Mental Health Initiative to expand SOC nationally.

Initially, federal funding was pitifully small, ($4.5 million in 1993). But it grew over the next 20 years to over $100 million per year, and cumulatively the federal government invested roughly $1.5 billion in 300 projects to model and seed the development of systems around the country.[2, 3] States and foundations have also invested in the development of various models of SOC. In addition, most of the demonstration projects have used other funding sources such as Medicaid to pay for services, resulting in far more funding than SAMHSA's grants alone.

Currently, SAMHSA is funding over 100 grants to expand and/or sustain systems of care.[4]

<u>What Is A System of Care?</u>

As originally conceived, a system of care is designed to improve the lives and clinical conditions of children and adolescents with **serious** emotional disturbance and their families. These are children who often have been victims of abuse and/or neglect, are in foster care, are failing in school, are in trouble with the law, etc.

According to SAMHSA a system of care is:

"A coordinated network of community-based services and supports organized to meet the challenges of children and youth and their families. System of care services should be

- child centered
- family driven;
- individualized, strengths based, and evidence informed;
- youth guided;
- culturally and linguistically competent;

- provided in the least restrictive environment;
- community based;
- accessible;
- collaborative and coordinated across an interagency network."[5]

Improved mental health is one of the goals of a system of care. But there are other goals that are equally or even more important. They include:

- living in the community rather than an institution
- having a caring, preferably permanent family
- being physically healthy
- avoiding adverse, traumatic experiences, especially violence
- reducing risk of suicide
- getting an education
- avoiding substance abuse
- avoiding crime and detention for criminal acts
- and more.

Outcomes of SOC

Although evaluations of SOC have had mixed results, there appears to be a consensus that SOC is generally beneficial. SAMHSA claims that SOC participants show:

- improved clinical condition, including reduced symptoms of anxiety and depression,
- reduced suicidal thoughts and attempts
- reduced use of inpatient care
- improved functioning
- improved educational outcomes
- improved living situations
- reduced law enforcement contact
- reduced caregiver strain
- reduced costs of care.[6]

Despite this evidence of success, SOC has yet to expand to scale in the United States. Yes, the federal government has helped to fund 300 initiatives since 1993, but there are over 3100 counties in the United States.[7] Many states have also funded some SOC efforts—such as the Coordinated Children's Services Initiative (CCSI) in New York State—but it seems safe to say that despite all of this, SOC has spread far more in concept than in reality.

Beyond Systems of Care

The passage of the Affordable Care Act (ACA), which is—unfortunately—generally referred to as "Obamacare", has led to a variety of efforts to restructure behavioral health service delivery and financing. This appears to be resulting in reduced efforts to expand systems of care as defined in the 1980s and 90s. Instead a process referred to in this issue of Behavioral Health News as "transforming systems of care" seems to be underway.

In fact, however, this process began a decade or more ago, some years before the ACA was enacted. For example, in 2006 Jane Knitzer herself argued that the child mental health system should move "beyond integration" and beyond the population of children and adolescents with **serious** emotional disturbance. She argued that the policy that arose from her own report in 1982 is "short-sighted public policy" and "no longer justified" and called, among other things, for providing early intervention for children and adolescents first exhibiting signs of mental illness and for preventive interventions that could reduce the incidence of emotional disturbance altogether.[8]

In 2008, the National Center for Children in Poverty followed up with a study entitled *Unclaimed Children Revisited*,[9] which noted shortfalls of the SOC experience and called for adopting a public health approach to child mental health. Such a population health approach would move beyond children with **serious** emotional disturbance and make efforts to promote mental health, prevent emotional disturbance, intervene early, and provide high quality, evidence-based treatment and other interventions for all children.

The move to go beyond SOC has accelerated since the passage of the ACA. For example, Mary Evans from the University of South Florida—which was a major site of early work on SOC—has been working with other colleagues from around the country to identify new opportunities to improve child and adolescent mental health created by the ACA. They have edited a special section of the *Journal of Orthopsychiatry* to discuss these opportunities.[10]

Like the earlier work of Knitzer and Cooper, Evans and her colleagues stress the importance of developing a public health approach that stresses prevention as well as high quality interventions. They view the emphasis in the ACA on integrating behavioral health care with primary, physical health care and new structures such as "medical homes" as a great opportunity for early identification, early intervention, and even the promotion of emotional health for the overall population of children and adolescents.

But while they welcome new opportunities, they also emphasize the importance of building on the experience of SOC and of preserving its core values of community-based care that is culturally competent, family driven, and integrated across "administrative and funding jurisdictions."

Matters of Concern

As much as I admire efforts to bring public health approaches to child mental health and share the hope we will ultimately treat emotionally disturbed children far more effectively than we do now and perhaps even prevent the development of mental disorders, I suspect that the ambition to go beyond systems of care is a product of the brilliance of human imagination, but simply unrealistic.

Why am I skeptical?

- After 35 years, SOC, despite its great popularity as a concept and less ambitious goals than the new public health approaches, still has not gone to scale. Will more ambitious redesign of systems be more successful?

- Current redesign of the child mental health system is largely being built on extensive use of managed care in Medicaid. How will these new systems reach the majority of America's children, who are covered by private health insurance rather than by Medicaid? It is true that, for example, New York State's Medicaid Redesign proposals for children speak to the need to link with commercial insurers.[11] But that is far easier said than done, especially on a national scale where there will be 50 different Medicaid redesigns and a need to link cooperatively with 50 different state insurance departments.

- Medicaid managed care still rests on applying a standard of medical necessity. Although there has been some movement towards seeing stable housing, for example, as a matter of medical necessity, we are still far, far away from using Medicaid to fund such non-medical services as special education, child welfare, and juvenile justice. Linkages across child serving systems are critical to improving outcomes for children and their families. It is not at all clear that Medicaid managed care can drive the necessary relationships and breadth of service.

- Requirements and incentives to integrate the delivery of primary physical health care and behavioral health services appear to be having limited impact—especially in the private sector where health providers have been slow to provide meaningful behavioral health services.

- Prevention—literal reduced incidence of mental and substance use disorders—is still more a hope than an achievable reality. It is true that the Institute of Medicine[12] and others have produced reports that document successful examples of "prevention." But a recent overview of meta-analyses of studies of preventive interventions concludes that while some show statistically significant positive outcomes, the effects are generally "small".[13] I'm afraid we have a long way to go for true and widespread prevention.

Conclusion:

There are many reasons to doubt that the effort to "transform systems of care" will have the desired outcomes. But there are also reasons to hope that a powerful commitment to the multiple aims of the Affordable Care Act—better care, better health, and contained costs—will pay off in the long run.

I hope that my skepticism is misplaced.

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