

Public Endorsement by AACAP of the Need for Family and Youth Involvement in Clinical Decision-Making

By Gordon R. Hodas, M.D.

Summary

In October 2009, the American Academy of Child and Adolescent Psychiatry (AACAP) endorsed a policy statement in support of family and youth participation in clinical decision-making. This paper reviews the rationale for family and youth participation in clinical treatment, and the significance of AACAP's policy statement for the field of mental health and human services. The actual AACAP policy statement is then presented in its entirety, so that stakeholders can use it to support this empowering, public health practice. This is followed by concluding comments.

Introduction

The importance of family and youth participation in treatment is well accepted within the public sector child and adolescent mental health community in Pennsylvania, and is being increasingly accepted by partnering child-serving systems as well (Family involvement in Pennsylvania's juvenile justice system, 2009; Family group decision making, 2008). Moreover, this core concept has been articulated by the [President's New Freedom Commission](#) (2003) and by the Institute of Medicine (2001). Within mental health at a national level, the concept is strongly supported by the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA), as part of its public health approach to treatment. For example, Gary Blau, Chief of the Child, Adolescent and Family Branch of CMHS, in association with the national [Federation of Families for Children's Mental Health](#), a family advocacy organization, has disseminated the concept of "family-driven, youth-guided" care (SAMHSA, 2009; Osher et al, 2008; National Federation, 2008). Further, a national youth advocacy organization, [Youth MOVE National, Inc.](#) (Motivating Others through the Voice of Experience) has been created with support from CMHS and the National Federation of Families. In addition, Kathryn Power, current CMHS Director, identifies family empowerment as an essential component of a public health approach to children's mental health, and envisions a system of care in which "service recipients direct their own care" (Power, 2009; Hodas, 2009).

Within Pennsylvania, the importance of family and youth participation in clinical care is clearly identified in [Pennsylvania's Child and Adolescent Service System Program \(CASSP\) Principles \(1995\)](#). Consistent with these principles and the recent federal initiative to support youth involvement in the system of care, Pennsylvania's Office of Mental Health and Substance Abuse Services (OMHSAS), in collaboration with youth, has developed a statewide Youth Advisory Committee to guide OMHSAS policy to parallel the ongoing efforts of statewide family advocates. In addition, "high fidelity wraparound," now being implemented on a pilot basis in Pennsylvania, upholds the importance of family and youth participation in care as an essential component of this model (Bruns, 2008).

A Different Paradigm

The importance of family and youth participation in clinical decision-making may now appear to be self-evident, but it is important to recognize that this concept and its related set of practices represent a

different paradigm from past common practice and from what many professionals learned in their training. It was not long ago that the predominant care concept was hierarchical in nature, with the professional as the expert defining the parameters of treatment and the family and youth as passive recipients of care, expected to “comply” with treatment as specified by the professional. The shift in paradigm occurred over time as a result of family advocacy (National Federation, 2008) and accumulating evidence that active participation by those receiving services is a key determinant – and perhaps the key determinant – of positive outcomes in mental health (Orlinsky et al, 2004; Bruns, 2008).

Despite its value, this paradigm shift, especially when not fully understood, can still be threatening to professionals. The collaborative paradigm, in fact, is not new, and in 1983, Don Schon, a social scientist, described the importance of “reflection in practice” and “reflective practitioners.” Schon argued that, in most areas of endeavor and not just mental health, collaborative, reflective relationships are a hallmark of successful practice (Schon, 1983).

AACAP’S Endorsement of Family and Youth Participation in Clinical Decision-Making

AACAP’s “Policy Statement: Family and Youth Participation in Clinical Decision-Making” was initially drafted by its Workgroup on Community-Based Systems of Care within the Academy. Part of the charge of the Workgroup is to “advocate for the development of comprehensive, youth guided, family driven, community-based, culturally competent, high quality and cost-effective systems of care” for children and adolescents with or at risk of developing serious emotional disturbances and their families (AACAP, 2009). The workgroup is comprised of child and adolescent psychiatrists from around the country who have been involved in community-based systems of care and who advocate for CASSP and system of care principles as practical and cost effective ways to address the challenging needs of children and adolescents and their families. The workgroup supports systematic efforts to identify a family’s strengths, needs and culture, the convening of a child and family team when indicated and a focus on collaboration and shared expertise. The workgroup also seeks to “educate and prepare child and adolescent psychiatrists to incorporate systems of care approaches into their clinical practice and to assume significant roles in the development and implementation of such systems” (AACAP, 2009). It is within this context that the policy statement was developed.

The majority of child and adolescent psychiatrist members of AACAP do not work in community-based systems of care. Many are involved in private practice, education, or clinical research, settings that may sometimes maintain the traditional hierarchy of the doctor-patient relationship. For this reason, formal endorsement by AACAP of the importance of family and youth participation in clinical decision-making represents a historic moment for the mental health field. By endorsing this policy statement, AACAP is defining the promotion of family and youth participation in clinical treatment as a core function of child and adolescent psychiatrists and, by implication, of clinicians in general.

The AACAP Policy Statement

Below is the body of AACAP’s [“Policy Statement: Family and Youth Participation in Clinical Decision-Making”](#) (2009), as approved by Council in October 2009:

Families and youth, as developmentally appropriate, must have a primary decision-making role in their treatment. The Institute of Medicine indicates that health care system redesign needs to involve “care customized according to patient needs and values,” with “the patient (as) the

source of control” (2001). The promotion of family participation and empowerment is referred to as “family-driven care,” with the family recognized as an equal partner with mental health and other human service professionals. Taking into account the need for active youth participation as well, care should be “family-driven and youth-guided.” The concept of family-driven, youth-guided care is further endorsed in the report of the President’s New Freedom Commission (2003). There is evidence that outcomes improve when family and youth participate actively in treatment (Morrisey-Kane & Prinz, 1999; Wehmeyer & Palmer, 2003). Family and youth engagement and subsequent commitment to treatment are heightened when they have leadership roles in clinical decision-making.

Families, youth and professionals have different sets of knowledge, experience and beliefs. All parties involved thus bring their unique expertise to the treatment team, without which the clinical decision-making process would be less productive. Family perspective is based on a family’s experience with their child and an understanding of their child and family’s strengths, needs, community, and culture. Youth perspective is based on the youth’s lived experience and priorities. Professional perspective is based on training, cumulative clinical experience, and the ability to listen carefully and respectfully to others. Mutual respect for each perspective promotes decision-making in the best interest of the child.

Family and youth involvement is essential at each phase of the treatment process, including assessment, treatment planning, implementation, monitoring, and outcome evaluation. Family and youth partnership also needs to inform decision making at the policy and systems level. Family priorities and resources must be identified and should drive care. Throughout the treatment process families and youth must:

- *have the right to be involved in making decisions regarding providers and others involved in the treatment team;*
- *be encouraged to express preferences, needs, priorities, and disagreements;*
- *collaborate actively in treatment plan development and in identifying desired goals and outcomes;*
- *be given the best knowledge and information to make decisions;*
- *make joint decisions with their treatment team; and*
- *participate actively in monitoring treatment outcomes and modifying treatment.*

Child psychiatrists should always work towards consensus among all parties in the clinical decision process. However, under extreme situations, legal mandates or safety concerns may need to take precedent.

Working together, family, youth, and professionals can collaborate effectively in support of individualized, strengths-based, culturally competent treatment.

Conclusions

The field of children’s mental health has made enormous progress, when we realize that, for the most part, the needs of children and adolescents and their families were not addressed by the federal Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, or by states and local communities at that time. Indeed, few states had the infrastructure or staff to identify and address

the needs of children and adolescents and their families. Through the efforts of Jane Knitzer (1982) and Ira Lourie at the National Institute of Mental Health shortly thereafter (Lourie, Katz-Leavy, DeCarolis & Quinlan, 1996), public sector children's mental health became part of the national agenda, and more recently, part of the public health approach to children's mental health (Power, 2009).

Although there are enormous benefits to a collaborative model of treatment and care, such a paradigm shift can also be very threatening to professionals who were trained and practice in a more traditional care model. In general, professional organizations, however well-intentioned their members might be, are slow to change. Therefore, the AACAP endorsement of the policy statement, "Family and Youth Participation in Clinical Decision-Making," is laudable and worthy of dissemination. This policy statement, directing professionals to empower families and youth, also advances a public health approach to mental health and human services. AACAP's endorsement has potential implications for individual practitioners within mental health and human services and for multiple professional organizations. As stakeholders, we can collectively encourage professional organizations to join AACAP in the commitment to collaborative care. In so doing, we support an approach to treatment and care best suited to help families build on opportunities and address challenges jointly with professionals, effectively promoting the positive development and wellbeing of youth and their families.

Gordon R. Hodas, M.D. is statewide child psychiatric consultant to the Office of Mental Health and Substance Abuse Services. He is also a member of the Systems of Care Workgroup of the American Academy of Child and Adolescent Psychiatrists.

References

Achieving the promise: Transforming mental health care in America. (2003). Final Report. New Freedom Commission on Mental Health. Rockville, MD: Department of Health and Human Services.

Bruns, E. (2008). The evidence base and wraparound. In Bruns, E. and Walker, J. (Eds.), *The Resource Guide to Wraparound* (pp. 1-12). Portland, OR: National Wraparound Initiative, Research and Training Center for Family Support and Children's Mental Health.

Charge of workgroup on community-based systems of care. (2009). American Academy of Child and Adolescent Psychiatry.

Core principles of the Pennsylvania Child and Adolescent Service System. (1995). Harrisburg, PA: Office of Mental Health and Substance Abuse Services.

Crossing the quality chasm: A new health system for the 21st century. (2001). Institute of Medicine, Committee on Quality of Health Care in America. Washington, DC: National Academy Press.

Family and youth participation in clinical decision-making. (2009). Policy Statement of the American Academy of Child and Adolescent Psychiatry. Washington, DC: American Academy of Child and Adolescent Psychiatry. Retrieved December 2, 2009, from http://www.aacap.org/cs/root/policy_statements/family_and_youth_participation_in_clinical_decisionmaking.

Family-driven – defined. (n.d.). National Federation of Families for Children’s Mental Health. Retrieved December 2, 2009, from <http://ffcmh.org/family-driven/>.

Family-driven and youth-guided systems. (n.d.). Rockville, MD: Substance Abuse and Mental Health Services Administration. Retrieved December 2, 2009, from www.systemsofcare.samhsa.gov/ResourceGuide/systems.html.

Family group decision making. (2008). Mechanicsburg, PA: Pennsylvania Child Welfare Training Program. Retrieved December 2, 2009, from www.pacwcbt.pitt.edu/FGDM.htm.

Family involvement in Pennsylvania’s Juvenile Justice system. (2009). Family Involvement Subcommittee of the Mental Health/Juvenile Justice Workgroup for Models of Change, Pennsylvania and Family Involvement Workgroup of the Pennsylvania Council of Chief Juvenile Probation Officer’s Balanced and Restorative Justice Implementation Committee. Harrisburg: Models Of Change, Systems Reform in Juvenile Justice.

Hodas, G. (2009). Advancing a public health approach to children’s mental health in Pennsylvania. Harrisburg, PA: Office of Mental Health and Substance Abuse Services.

Knitzer, J. (1982). Unclaimed children: The future of public responsibility to children and adolescents in need of mental health services. Washington DC: Children’s Defense Fund.

Lourie, I., Katz-Leavy, J. DeCarolis, G., & Quinlan, W. (1996). The role of the federal government. In Stroul, B. (Ed.), *Children’s Mental Health: Creating Systems of Care in a Changing Society*. Baltimore: Brookes Publishing Company.

Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. (1963). Public Law 88-164. Washington, DC: United States Congress.

Morrissey-Kane, E. & Prinz, R. (1999). Engagement in child and adolescent treatment: The role of parental cognitions. *Clinical Child and Family Review*, 2, 183-198.

Orlinsky, D., Ronnestad, M., & Willutzki, Y. (2004). Fifty years of process-outcome research. In Lambert, M. (Ed.). *Bergen and Garfield’s Handbook of Psychotherapy and Behavior Change* (5th ed.). New York: Wiley.

Osher, T., Osher, D., & Blau, G. (2008). Families matter. In Gullotta, T. and Blau, G. (Eds.): *Family Influences on Childhood Behavior and Development: Evidence-Based Prevention and Treatment Approaches*, pp. 39-61. New York, NY: Routledge.

Power, K. (2009). A public health model of mental health for the 21st century. *Psychiatric Services* (60)5, 580-584.

Schon, D. A. (1983). *The Reflective Practitioner: How Professionals Think in Action*. New York, NY: Basic Books.

Wehmeyer, M. & Palmer, S. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38* (2), 131-144.