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## III. Concluding Observations

### Common Characteristics and Challenges

- **Common Characteristics**

While the three states' approaches to family involvement in managed care systems described in this paper are unique each in its own way, they also share a number of common characteristics:

- **Values-based designs** are characteristic of these approaches, with values based on CASSP-liked principles that are relevant to children and their families. It is essential to have CASSP-like principles as a central organizing concept in managed care systems. These values place families in a leadership role in determining the course of the care their family member receives.
- **State level administrative structures.** All these approaches demonstrate state level administrative rules reflecting the will of state government to simply say “meaningful family involvement shall be”, and written policy guidelines established at the agency or organization level reflecting buy-in by agency administrators. The very administrative personnel who created the written policy guidelines are often the same individuals who serve on the board or committee with family member representatives. Family partnerships were deliberately structured at policy, management and service delivery levels.
- **Money.** True family involvement in managed care requires money. There is no integrated family involvement unless some means is found to pay those involved in such a way that allows commitment to the task on the part of family representatives. In addition to equal pay for equal work, funds were provided by these states to: pay travel expenses for family members to get to events, meetings, and activities; develop the infrastructure of family run organizations; develop new systems capacity, etc. Financial support is crucial for the survival and ongoing viability of family organizations to ensure networks of informal community resources.
- **Family run not-for-profit organizations.** The family members who governed the family organizations were key players in the development of culturally competent team centered local systems of care. Although each family organization had a set of ideas and objectives based on their collective family voices, one goal they shared was to partner with professionals working with children with serious behavioral health challenges to create a system of care that is responsive to families' needs and strengths.
- **Access is a hallmark** of all these approaches — access to information, to how things work politically and systemically, and access and participation in the dialogue of philosophies and political realities as they play out in each state's public life and policy. The approaches share a willingness to capitalize on every opportunity to include the parent voice at every relevant table and to share power.
- **Family members as quality assurance employees.** The approaches share a commitment to support and develop family members' involvement in the quality improvement processes relevant to children and data-based decision making . Family members at both the service and systems levels are able to see problems reported (data collected) and used to guide policy and service decision making.

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## • Common Challenges

- **Time and Resources.** A change in personnel at the state or county level can affect the support families have received to expand the family voice. It takes time to develop relationships and build partnerships. It takes time to bring the message of families to professionals — the new way of viewing families as well as the importance of family involvement in services and supports. It takes time to build family support networks and time is a precious commodity in families struggling to raise a child with serious behavioral health challenges.
- **Ongoing Education, Information, and Training.** Educating families in a number of critical areas is a continual challenge for these systems. Families need to have a basic understanding of managed care concepts, as well as an understanding of how the system operates, what managed care is, and what to expect. In addition, education and training is needed about the approach to care used in many of these systems for children with serious disorders (i.e., an individualized/wraparound approach, family focus, community-based services and supports, etc.). This challenge is complicated by the staff turnover that plagues many child-serving systems, especially among front-line workers. Further, families need information on what services are available, what they are entitled to, and how to access care.
- **Family Involvement Across Systems.** Although these promising approaches share a commitment to family involvement, this value is not always shared among front line staff or among partner agencies and systems. Respecting families as experts on their children, enlisting them as partners in their child's care, supporting them in their caregiver role, and involving them as partners in decision making at the system level are goals that have not been fully achieved in any of the systems. Handling resistance to family involvement and encouraging staff and partner agencies to understand and adopt this value requires attention, persistence, and funding.
- **Developing Family Leadership Skills.** Family leadership at the policy and management levels is crucial and may need to be nurtured by the organizational mentor and other state family leaders. Care needs to be taken to ensure families have the opportunity to identify those qualities, skills, and experiences they need to further their capabilities and help family members to develop them.