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Study 6: The Family Voice Study: Assessing the Role of Family Organizations in Developing Family Voice in Systems of Care

ASSUMPTIONS, INDICATORS, & DESCRIPTORS

Purpose:
To examine how family voice, as represented through family-run organizations, contributes to the implementation of effective systems of care.

Objectives:
1. To examine how effective family-run organizations are linked to effective and integrated systems of care;
2. To increase the field's understanding of the structures, processes, and relationships of family-run organizations in systems of care;
3. To test the factors that contribute to the development and sustainability of an effective family-run organization;
4. To examine and develop methods of diffusion that are anchored in its utilization for systems –of-care transformation

Research Questions:
1. How do family – run organizations contribute to the implementation of local systems of care?
2. How do family-run organizations contribute to the sustainability of local systems of care?
3. How are the systems-of-care implementation factors understood and operationalized from the perspective of family-run organizations?
4. What factors support or impede the development of family-run organizations in the context of systems of care?

Assumptions	Indicators	Descriptors
1) In an effective, integrated system of care, the value of family partnership in all aspect of the system is instilled throughout the operations of the system of care, including setting policies, developing programs, delivering services, and assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large.	How important is it that the value of family partnership be instilled in setting policies in a system of care?	Describe how the value of family partnership is communicated throughout the system of care?
	To what extent is the value of family partnership instilled in setting policies in your system of care?	
	How important is it that the value of family partnership be instilled in developing programs in a system of care?	
	To what extent is the value of family partnership instilled in developing programs in your system of care?	
	How important is it that the value of family partnership be instilled in delivering services?	
	To what extent is the value of family partnership instilled in delivering services?	

	How important is it that the value of family partnership be instilled in assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	
	To what extent is the value of family partnership instilled in assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	
2) In an effective, integrated system of care, the development and growth of a family-run organization to create capacity for recruiting, engaging, developing/training, supporting, and sustaining a diverse cadre of families who collectively and effectively are the "family voice" in shaping their community's response to children with mental health needs and their families is supported and sustained.	How important is the development and growth of a family-run organization to create capacity for family recruiting, engaging, developing/training, supporting, and sustaining a diverse cadre of families who collectively and effectively are the "family voice" in shaping their community's response to children with mental health needs and their families?	Describe how the system of care supports and sustains the development and growth of your Family Organization to create capacity for recruiting, engaging, developing/training, supporting, and sustaining a diverse cadre of families who collectively and effectively are the "family voice" in shaping their community's response to children with mental health needs and their families?
	To what extent does your Family Organization recruit, engage, develop/train, support, and sustain a diverse cadre of families who collectively and effectively are the "family voice" in shaping their community's response to children with mental health needs and their families is supported and sustained?	What is the base level of support (financial, material, personnel, and/or strategic) necessary for the system of care to provide for families to successfully develop and sustain your Family Organization?
	To what extent is your Family Organization supported to recruit, engage, develop/train, support, and sustain a diverse cadre of families who collectively and effectively are the "family voice" in shaping their community's response to children with mental health needs and their families?	Describe how the system of care supports your Family Organization in reaching out to and engaging a diverse cadre of families who are collectively the "family voice"?
3) In an effective, integrated system of care, the family-run organization is actively encouraged and supported in seeking to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a	How important is it that a family-run organization is actively encouraged and supported in seeking to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves?	Describe how the system of care actively encourages and supports your Family Organization in seeking to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a variety of capacities, and to enhance the child and

variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves.	To what extent does your Family Organization seek to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves?	adolescent workforce so that it is more diverse and representative of the community it serves? What particular strategies does the system of care utilize to encourage and support your Family Organization in seeking to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a variety of capacities, including family members representative of all groups served by the system of care? What particular strategies does the system of care utilize to encourage and support your Family Organization to enhance the child and adolescent workforce so that it is more representative of the community it serves?
	To what extent is your Family Organization actively encouraged and supported in seeking to recruit, engage, and nurture a number of diverse family leaders sufficient to interface consistently and effectively with the system of care in a variety of capacities, and to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves?	
	How important is it that a family-run organization is actively encouraged and supported in enhancing the child and adolescent workforce so that it is more diverse and representative of the community it serves?	
	To what extent does your Family Organization seek to enhance the child and adolescent workforce so that it is more diverse and representative of the community it serves?	
	To what extent is your Family Organization actively encouraged and supported in enhancing the child and adolescent workforce so that it is more diverse and representative of the community it serves?	
4) In an effective, integrated system of care, families and youth are involved in all aspects of the system and in a variety of capacities, including setting policies, developing programs, delivering services, and assessing the impact of the system of care of children, youth and families served, the collaborating agencies and systems, and the community at large.	How important is it that adult family members be involved in setting policies within the system of care?	Describe how the system of care involves families and youth in all aspects of the system and in a variety of capacities, including setting policies, developing programs, delivering services, and assessing the impact of the system of care of children, youth and families served, the collaborating agencies and systems, and the community at large? What are the opportunities and challenges associated with family and youth involvement in
	To what extent are adult family members involved in setting policies within the system of care?	
	To what extent are adult family members actively encouraged and supported to be involved in setting policies within the system of care?	
	How important is it that a family-run organization be involved in setting policies within the system of care?	
	To what extent is your Family Organization involved in setting policies within the system of care?	

		To what extent is your Family Organization actively encouraged and supported to be involved in setting policies within the system of care?	these various capacities?
		How important is it that adult family members are involved in developing programs within the system of care?	What are the strategies utilized by the system of care to support your Family Organization in translating evidenced-based research into tools that can assist families to be stronger advocates for their children, effective peer supports, and effective system partner?
		To what extent are adult family members involved in developing programs within the system of care?	
		To what extent are adult family members actively encouraged and supported to be involved in developing programs within the system of care?	
		How important is it that a family-run organization be involved in developing programs within the system of care?	What are the strategies utilized by your Family Organization in translating evidenced-based research into tools that can assist families to be stronger advocates for their children, effective peer supports, and effective system partner?
		To what extent is your Family Organization involved in developing programs within the system of care?	
		To what extent is your Family Organization actively encouraged and supported by the system of care to be involved in developing programs within the system of care?	
		To what extent does your Family Organization actively encourage and support adult family members to be involved in developing programs within the system of care?	
		How important is it that adult family members be involved in delivering services?	
		To what extent are adult family members involved in delivering services within the system of care?	
		How important is it that a family-run organization be involved in delivering services?	
		To what extent is your Family Organization involved in delivering services within the system of care?	
		To what extent is your Family Organization actively encouraged and supported by the system of care in delivering services within the system of care?	
		To what extent does your Family Organization actively encourage and support the involvement of adult family members in delivering services within the system of care?	
		How important is it that adult family members are involved in assessing the impact of the system of care on children, youth and families served?	

		How important is it that adult family members be involved in assessing the impact of the system of care on the collaborating agencies and systems?	
		How important is it that adult family members be involved in assessing the impact of the system of care on the community at large?	
		To what extent are adult family members involved in assessing the impact of the system of care on children, youth and families served?	
		To what extent are adult family members involved in assessing the impact of the system of care on the collaborating agencies and systems?	
		To what extent are adult family members involved in assessing the impact of the system of care on the community at large?	
		To what extent is your Family Organization involved in assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	
		How important is it that a family-run organization be involved in assessing the impact of the system of care on children, youth and families served?	
		How important is it that a family-run organization be involved in assessing the impact of the system of care on the collaborating agencies and systems?	
		How important is it that a family-run organization be involved in assessing the impact of the system of care on the community at large?	
		To what extent is your Family Organization involved in assessing the impact of the system of care on children, youth and families served?	
		To what extent is your Family Organization involved in assessing the impact of the system of care on the collaborating agencies and systems?	
		To what extent is your Family Organization actively encourage and supported to be involved in assessing the impact of the system of care on the community at large?	
		To what extent does your Family Organization involve adult family members in assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	

	How important is it that youth are involved in setting policies?	
	To what extent does your Family Organization involve youth in setting policies?	
	How important is it that youth are involved in developing programs?	
	To what extent does your Family Organization involve youth in developing programs?	
	How important is it that youth are involved in delivering services?	
	To what extent does your Family Organization involve youth in delivering services?	
	How important is it that youth are involved in assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	
	To what extent does your Family Organization involve youth assessing the impact of the system of care on children, youth and families served, the collaborating agencies and systems, and the community at large?	
5) In an effective, integrated system of care, family members (including youth) operate in a peer support role to assist other families and youth in navigating systems, in providing information and emotional support.	How important is it that adult family members operate in a peer support role to assist other families in navigating systems?	Describe how the system of care supports your Family Organization and family members (including youth) to operate in a peer support role to assist other families and youth in navigating systems, in providing information and emotional support?
	To what extent do policies and practices of the system of care encourage and support individual family members to operate in a peer support role to assist families in navigating systems?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization to help family members operate in a peer support role to assist families in navigating systems?	What are some of the peer support roles and arrangements in your system of care for families and youth?
	To what extent does your Family Organization support and encourage family members to operate in a peer support role to assist families in navigating systems?	
	How important is it that adult family members operate in a peer support role to assist other families in providing information?	
	To what extent do policies and practices of the system of care encourage and support individual family members to operate in a peer support role to assist families in providing information?	

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	To what extent do policies and practices of the system of care encourage and support your Family Organization to help family members operate in a peer support role to assist families in providing information?	
	To what extent does your Family Organization support and encourage family members to operate in a peer support role to assist families in providing information?	
	How important is it that adult family members operate in a peer support role to assist other families in providing emotional support?	
	To what extent do policies and practices of the system of care encourage and support individual family members to operate in a peer support role to assist families in providing emotional support?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization to help family members operate in providing emotional support?	
	To what extent does your Family Organization support and encourage family members to operate in a peer support role to assist families in providing information?	
	To what extent do policies and practices of the system of care encourage and support family members to operate in a peer support role to assist families and youth in navigating systems, in providing information and emotional support?	
	How important is it that youth operate in a peer support role to assist other youth in navigating systems?	
	To what extent do policies and practices of the system of care encourage and support individual youth to operate in a peer support role to assist families and youth in navigating systems?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization or a Youth Organization to operate in a peer support role to assist families and youth in navigating systems?	
	To what extent does your Family Organization encourage and support youth to operate in a peer support role to assist families and youth in navigating systems?	
	How important is it that youth operate in a peer support role to assist other youth in providing information?	
	To what extent do policies and practices of the system of care encourage and support individual youth to operate in a peer support role to assist other youth in providing information?	

	To what extent do policies and practices of the system of care encourage and support your Family Organization or a Youth Organization to operate in a peer support role to assist other youth in providing information?	
	To what extent does your Family Organization encourage and support youth to operate in a peer support role to assist youth in providing information?	
	How important is it that youth operate in a peer support role to assist other youth in providing emotional support?	
	To what extent do policies and practices of the system of care encourage and support individual youth to operate in a peer support role to assist youth in providing emotional support?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization or Youth Organization to operate in a peer support role to assist youth in providing emotional support?	
	To what extent does your Family Organization encourage and support youth to operate in a peer support role to assist youth in providing emotional support?	
6) In an effective, integrated system of care, a family-run organization is encouraged and supported to help families access the system.	How important is it that family members help families access services and supports?	Describe the policies and practices of the system of care that encourage and support family-run organizations to help families access the system? Describe what your Family Organization is doing to help families access the system.
	To what extent do policies and practices of the system of care encourage and support individual family members to help families access services and supports?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization to help family help families access services and supports??	
7) In an effective, integrated system of care, a family-run organization plays a key role in helping to ensure the type and quality of services provided.	How important is it that family-run organizations play a key role in helping to ensure the type and quality of services provided?	Describe how the system of care encourages and supports your Family Organization to play a key role in helping to ensure the type and quality of services provided.

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	To what extent does the system of care support and encourage <u>individual family members</u> to have a key role in helping to ensure the type and quality of services provided?	
	To what extent does the system of care support and encourage your <u>Family Organization</u> to have a key role in helping to ensure the type and quality of services provided?	
	To what extent does your Family Organization support and encourage individual family members to have a key role in helping to ensure the type and quality of services provided?	
8) In an effective, integrated system of care, a family-run organization has productive working relationships with state and local agencies (i.e., purchasers) and with providers in order to strengthen policy commitment and service delivery to children with mental health needs.	How important is it that family-run organizations have productive working relationships with local agencies?	Describe the types of working relationships that your Family Organization has with state agencies.
	To what extent do policies and practices of the system of care encourage and support your Family Organization to have productive working relationships with local agencies?	Describe the types of working relationships that your Family Organization has with local agencies?
	To what extent does your Family Organization have productive working relationships with local agencies?	
	How important is it that family-run organizations have productive working relationships with state agencies?	Describe the types of working relationships that your Family Organization has with providers?
	To what extent do policies and practices of the system of care encourage and support your Family Organization to have productive working relationships with state agencies?	What are the opportunities and challenges associated with these working relationships?
	To what extent does your Family Organization have productive working relationships with state agencies?	What is the "value-added" of these working relationships?
	How important is it that family-run organizations have productive working relationships with providers?	
	To what extent do policies and practices of the system of care encourage and support your Family Organization to have productive working relationships with providers?	
	To what extent does your Family Organization have productive working relationships with providers?	
9) In an effective, integrated system of care, mechanisms are in place to sustain a family-run organization.	How important is it that a system of care has mechanisms in place to sustain a family-run organization?	Describe the system of care mechanisms in place to sustain your Family Organization.
	To what extent does the system of care have mechanisms in place to sustain your Family Organization?	Describe the activities of your Family Organization related to sustainability.

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	To what extent does your Family Organization engage in activities aimed at sustaining the organization?	
10) In an effective, integrated system of care, a family-run organization is supported and encouraged to develop skills and knowledge and engage families in changing policy through legislative strategies to focus on child and adolescent mental health needs.	How important is it that a system of care encourages and supports a family-run organization to train and engage families in policy through legislative strategies to focus on child and adolescent mental health needs?	Describe how the system of care encourages and supports your Family Organization to train and engage families in policy through legislative strategies to focus on child and adolescent mental health needs.
	To what extent does the system of care encourage and support your Family Organization to train and engage families in policy through legislative strategies to focus on child and adolescent mental health needs?	
	To what extent your Family Organization train and engage families in policy through legislative strategies to focus on child and adolescent mental health needs?	
11) In an effective, integrated system of care, a family-run organization is encouraged and supported to meet the needs and requests of all families in their system of care community (e.g., legal advice about school suspension, medication questions, etc.).	How important is it that a family-run organization meets the related needs (e.g., legal advice about school suspension, medication questions, etc.) of all families in their system of care community?	Describe how the system of care encourages and supports your Family Organization to meet the related needs (e.g., legal advice about school suspension, medication questions, etc.) of all families in their system of care community?
	To what extent does the system of care encourage and support your Family Organization to meet the related needs (e.g., legal advice about school suspension, medication questions, etc.) of all families in their system of care community?	
	To what extent does your Family Organization meet the related needs (e.g., legal advice about school suspension, medication questions, etc.) of all families in their system of care community?	
12) In an effective, integrated system of care, families have direct connections to mental health providers and other child serving agencies, and support family organizations to assist families to have direct access.	How important is it that families have direct connections to mental health providers and other child serving agencies?	Describe how policies and practices of the system of care allow families to have direct connections to mental health providers and other child serving agencies (and support family organizations to assist families to have direct access)?
	To what extent does the system of care have policies and practices that allow families to have direct connections to mental health providers and other child serving agencies (and support family organizations to assist families to have direct access)?	
	To what extent does your Family Organization assist families to have direct access to mental health providers and other child serving agencies?	

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