Washington State
Department of Social & Health Services

Report to the Legislature

Strategies for Developing Consumer and Family Run Services

Substitute House Bill (SHB) 2654

September 2008

Report to the Legislature on Substitute House Bill (SHB) 2654: Strategies for Developing Consumer and Family Run Services

September 2008

submitted to

The State of Washington
Department of Social and Human Services
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Mental Health Division

by the

SHB2654 Work Group

supported by

▼TRIWEST GROUP
6549 First Avenue NW
Seattle, WA 98117

SHB2654 Work Group Members

Name	Affiliations
Stakeholder Representatives	
Sue Allen	Capital Clubhouse / Washington State Clubhouse Coalition
Brad Berry	Consumer Voices Are Born (CVAB)
Cathy Clem	North Sound Mental Health Family Groups
Judie Ebbert-Rich	A Village Project II
Dawn Grosz	Statewide Action for Family Empowerment of Washington (SAFE WA)
Mary Jadwisiak	MATAC
Tamara Johnson	Youth 'N Action – Co-Program Director and Youth Advocate
Dominic King	Youth 'N Action – Youth Advocate
Cathii Nash	Mental Health Planning and Advisory Council
Don Nichols	Rising Sun Clubhouse
Margaret Rojas	North Sound RSN
Ken Stark, Ron Jemelka	Mental Health Transformation Project
Clifford Thurston	New Century Empowerment Project
Laura Van Tosh	Western State Hospital
Lenora Warden	Consumer Advocate
Bill Waters	Val Ogdon Center / Washington State Clubhouse Coalition / National Alliance on Mental Illness Board Member
Aunrico Williams	Youth 'N Action – Youth Advocate
Mental Health Division Staff	
Karie Castleberry	Mental Health Division
Frank Jose	Mental Health Division
Richard Kellogg	Mental Health Division
Stephanie Lane	Mental Health Division
Tony O'Leary	Mental Health Division
Andy Toulon	Mental Health Division
Jessica Bayne	Mental Health Division
TriWest Group Staff	
Andy Keller	TriWest Group
Bill Wilson	TriWest Group

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Executive Summary

Substitute House Bill (SHB) 2654 directed the Washington State Department of Social and Health Services (DSHS) Mental Health Division (MHD) to prepare a report on strategies for developing consumer and family run services. MHD convened a Work Group of mental health consumers, youth in transition, family members, and stakeholders to develop the report. The principle of **Recovery** undergirds the values of consumer and family run organizations serving adults, and **System of Care** values guide the operations of youth and family run organizations focusing on children, youth, youth in transition, and families. The report centers on the concept of **Consumer and Family Run Organizations** that emphasize self-help as their operational approach and that are owned, administratively controlled, and operated by mental health consumers or their families with the following five qualities:
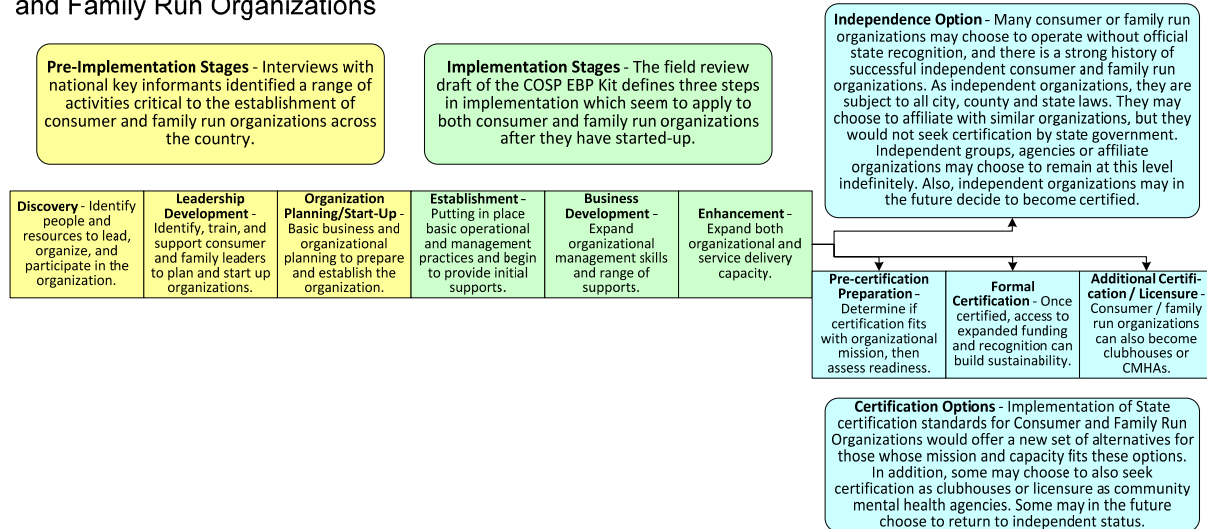
- **Independent:** The organization is controlled and operated by consumers (for consumer run organizations) or family members (for family run organizations);
- **Autonomous:** Decisions about governance, fiscal, personnel, policy, purchasing, quality improvement, and all operational matters are made by the organization;
- **Accountable:** Responsibility for decisions rests with the organization;
- **Consumer / Family Controlled:** At least 51% of the governance board are consumers(for consumer run organizations) or family members (for family run organizations); and
- **Peer Workers:** Staff and management have received mental health services (or, for family members, are related to a person who has received mental health services) and they have life experiences that are relevant and similar to the people whom they serve.

The Work Group reviewed the rich histories of consumer, youth, parent/caregiver, and family member run services and supports, as well as the evidence bases demonstrating effectiveness and contributions to the public mental health system across decades. Consumer and family run organizations currently operating in Washington State include long-standing consumer run organizations like Thurston County's Capital Clubhouse and Clark County's Consumer Voices are Born, as well as newer groups like the cross-state New Century Empowerment Project; youth run organizations such as the statewide Youth 'N Action program; parent / caregiver run organizations like King County's A Village Project II and Statewide Action for Family Empowerment of Washington network organizations, including A Common Voice for Pierce County, BRIDGES to Parent Voice (Clallam, Kitsap, and Jefferson Counties), Changes Parent Support Network (King and Snohomish Counties), Spokane's Passages program, and Training Resources in Partnership (Island, San Juan, Skagit, Snohomish, and Whatcom Counties); and family run organizations such as the 23 National Alliance on Mental Illness (NAMI) affiliates statewide. The Mental Health Planning and Advisory Council's recommendations prioritized consumer and family run organizations in Washington's Fiscal Year 2009 plan submitted to the Substance Abuse and Mental Health Services Administration. Such services and supports can achieve significant outcomes, and their success is demonstrated daily in the lives of people with mental illness and their families, as well as within the published literature. The Work Group concluded: ***Washington State needs a broader and diverse array of consumer and family run organizations to develop and provide an ever-expanding array of services and supports grounded in the priorities of the consumers and family members that live in the communities where those programs operate.***

As with every type of business, consumer and family run organizations have a mixed history of success nationally and in Washington State. When defining "success," it is important to recognize the multiple levels of development needed to successfully implement consumer and family run organizations, as summarized in the figure that follows.

Developmental Framework for Consumer
and Family Run Organizations

| **Pre-Implementation Stages** - Interviews with national key informants identified a range of activities critical to the establishment of consumer and family run organizations across the country. | **Implementation Stages** - The field review draft of the COSP EBP Kit defines three steps in implementation which seem to apply to both consumer and family run organizations after they have started-up. | **Independence Option** - Many consumer or family run organizations may choose to operate without official state recognition, and there is a strong history of successful independent consumer and family run organizations. As independent organizations, they are subject to all city, county and state laws. They may choose to affiliate with similar organizations, but they would not seek certification by state government. Independent groups, agencies or affiliate organizations may choose to remain at this level indefinitely. Also, independent organizations may in the future decide to become certified. |

| **Discovery** - Identify people and resources to lead, organize, and participate in the organization. | **Leadership Development** - Identify, train, and support consumer and family leaders to plan and start up organizations. | **Organization Planning/Start-Up** - Basic business and organizational planning to prepare and establish the organization. | **Establishment** - Putting in place basic operational and management practices and begin to provide initial supports. | **Business Development** - Expand organizational management skills and range of supports. | **Enhancement** - Expand both organizational and service delivery capacity. |

| **Pre-certification Preparation** - Determine if certification fits with organizational mission, then assess readiness. | **Formal Certification** - Once certified, access to expanded funding and recognition can build sustainability. | **Additional Certification / Licensure** - Consumer / family run organizations can also become clubhouses or CMHAs. |

Certification Options - Implementation of State certification standards for Consumer and Family Run Organizations would offer a new set of alternatives for those whose mission and capacity fits these options. In addition, some may choose to also seek certification as clubhouses or licensure as community mental health agencies. Some may in the future choose to return to independent status.

To promote the development of such organizations, the following recommendations are made:

- Fund **technical assistance to develop consumer and family run organizations across the state** at multiple levels of development, including dedicated funding for both the start-up of new organizations and the enhancement of existing organizations. Technical assistance should also support RSNs and CMHAs to integrate their services with those of consumer and family run organizations. This should be funded from multiple sources.
- **Develop certification requirements to ensure accountability for consumer and family run organizations** by July 1, 2009, building on the successful structure and approach developed for MHD's clubhouse certification requirements.
- In order to ensure the provision of adequate technical assistance, coordinate with existing services, and evaluate the effectiveness of the organizational development process, fund and **implement a pilot of at least two consumer run and two family run organizations** to establish their initial certification under the new requirements by January 1, 2010.
- **Refine the certification requirements through an evaluation** to assess the effectiveness of the certification requirements and technical assistance in supporting the development of the pilot sites, as well as their potential for replication by July 1, 2011.
- Recommendations for Washington's Medicaid State Plan and 1915(b) waiver include:
  1. **Do not amend the Medicaid State Plan.** Washington's Medicaid State Plan is sufficient to support services by consumer and family run organizations.
  2. **Add language to the 1915(b) Waiver recognizing properly credentialed Certified Consumer and Family Run Organizations as eligible providers of Peer Support and select (b)(3) services.** MHD should add such language for Peer Support and consider adding language to the (b)(3) definitions of respite and supported employment to allow them to be delivered with "consultation" (as an alternative to "supervision") by a mental health professional if the service is delivered by a consumer or family run organization.

Section 1 – Introduction

The Washington State Department of Social and Health Services (DSHS) Mental Health Division (MHD) engaged TriWest Group (TriWest) to facilitate a multi-stakeholder Work Group to collaborate with MHD to respond to the requirements of Substitute House Bill (SHB) 2654. SHB 2654 directed DSHS to prepare a report on strategies for developing consumer and family run services. In response to that legislation, Washington State MHD Director Richard Kellogg convened a Work Group of mental health consumers, youth in transition, family members, and other mental health stakeholders to develop the report in cooperation with MHD, including:

> The principle of **Recovery** undergirds the values of consumer and family run organizations serving adults, with an emphasis on self-direction, individualized and person centeredness, empowerment, holistic approaches, nonlinear pathways, strengths, peer support, respect, responsibility and hope. **System of care** values guide the operations of youth and family run organizations focusing on children, youth, youth in transition, and families, with an emphasis on family-driven, youth-guided care; strengths-based perspectives; family and youth involvement in all aspects of service planning and delivery; multi-agency and community-based collaboration; a broad, individualized, and flexible array of services and supports in the least restrictive, most appropriate settings; and responsiveness to the cultures and characteristics of populations served.

- Adult mental health consumers and advocates, including representatives of consumer run organizations,
- Youth consumers and advocates, including representatives of Youth 'N Action,
- Parents and caregivers of children and youth receiving mental health services, including representatives of SAFE-WA,
- Family members of adult consumers, including representatives of NAMI,
- Clubhouse advocates,
- Other advocates for youth and family services,
- A representative of the Regional Support Networks (RSNs), and
- MHD Office of Consumer Partnership and additional MHD staff to support implementation.

The Work Group and its various subcommittees met more than twenty times over a six month period including four face to face meetings and 16 conference calls. The report writing process involved the entire Work Group, with numerous members drafting key sections and all members reviewing and commenting on three full drafts of the report. External respondents from the Washington Community Mental Health Council and Regional Support Network (RSN) leadership reviewed the second draft and provided feedback as part of the Work Group's final meeting. National and state subject matter experts were also consulted in order to create a mosaic that includes the diverse cultural and linguistic needs of Washington, while seeking out the history and lessons learned from other states that have implemented and sustained consumer and family run services and programs. In order to develop strategies and requirements to promote the broadest possible implementation of consumer and family run services, the Work Group first developed some guiding definitions.

Definition of Consumer and Family. The Work Group took its primary guidance from the text of SHB 2654, which focuses on both consumers and families. In developing the definitions below, we also looked to existing state and federal sources that are discussed in more detail in Appendix One. The group added a specific emphasis on youth in transition, given their importance as a distinct subgroup among the broader array of consumers. Because of this, the Work Group recommended that a broad fabric of consumer and family run organizations be supported, consistent with SHB 2654 and the inclusive nature of Washington Administrative Code (WAC) definition of consumer (WAC 388-865-0150), with three distinct emphases:

> While the term **consumer** is often used to refer to people who have received public mental health services, people individually choose to use a wide array of terms to refer to themselves, including: **Mental Health Consumers**, **Consumers / Survivors**, **Psychiatrically Labeled**, **Ex-patients**, **Clients**, **Peers**, and other terms. All of these terms can be used to refer to individuals who have experienced or been diagnosed with a psychiatric disorder. In this report we use the term "consumer."

- **Consumers**, including any person who has applied for, is eligible for or who has received mental health services;
- **Parents, caregivers, and legal guardians of any child consumer** under the age of thirteen and, for a child age thirteen or older, those parents and legal guardians who are involved in the treatment plan of those children; and
- **Other family members**, including parents, foster parents, caregivers, and guardians of adults, as well as siblings, fictive kin, and significant others.

The diversity of consumers and families should also be considered when supporting the development of consumer and family run organizations, including the following dimensions:

- **Age**: Youth, youth in transition (between the ages of 17 and 26), adults, and older adults are all important subgroups, as are their respective family members.
- **Culture**: The races, ethnicities, languages, and cultures of local communities are key.
- **Social Status**: Consumers and family members face stigma, plus an array of economic hardships, and they must navigate the service systems despite these challenges.

SHB 2654 focuses on the organizations that deliver consumer and family services and supports, specifically consumer and family run organizations. Within the legislation text, SHB 2654 shifts language in its text from an initial emphasis on "consumer and family run organizations" to the term "community service agencies." This shift recognizes one important emphasis of the legislation, namely the potential to leverage Medicaid funding to support ongoing operations of consumer and family run organizations that deliver services. Given the broader mandate of SHB 2654 to promote consumer and family run organizations, this report centers on the concept of **Consumer and Family Run Organizations,** organizations that emphasize self-help as their operational approach and that are owned, administratively controlled, and operated by mental health consumers or their families. These organizations demonstrate the following five qualities:

- **Independent:** The organization is controlled and operated by consumers (for consumer run organizations) or family members (for family run organizations);

- **Autonomous:** Decisions about governance, fiscal, personnel, policy, purchasing, quality improvement, and all other operational matters are made by the organization and not an external entity;
- **Accountable:** Responsibility for decisions rests with the organization;
- **Consumer controlled:** At least 51% of the governance board are consumers(for consumer run organizations) or family members (for family run organizations); and
- **Peer workers:** Staff and management have received mental health services (or, for family members, are related to a person who has received mental health services) and they have life experiences that are relevant and similar to the people whom they serve.

The Work Group also emphasized the importance of youth run organizations. While youth in transition are a subset of consumers, they report that their particular concerns and experiences often differ from those of members of many consumer run organizations focused on adults. In addition, while they tend to share a common concern regarding services and supports with parent and caregiver run organizations that focus on youth services, their perspectives on these services often differ from those of families. Because of this, youth advocates involved in this process discussed the need to potentially define a separate set of definitions for "youth run organizations." Ultimately, the Work Group decided that, since youth are encompassed by the definition of consumer similar to other groups with specialized concerns, such as older adults or people with co-occurring disorders, it did not make sense to begin to proliferate multiple sub-definitions. Instead, we emphasize the role of youth in transition throughout the report.

> *My Youth Partner saved my life. She helped me through a very painful time of being on the streets, doing drugs, being separated from my family and making some very unhealthy decisions about my life. She was a role model for me, she helped me to see that there were many ways I could live my life with purpose and hope. The next time they offer the youth and parent partner training I plan to take the training and become a youth partner.*

Section 2 – Implementing Consumer and Family Run Services and Supports in Washington

Evidence Base for Consumer and Family Run Services and Supports

The Work Group carried out a review of the histories of consumer, youth, parent / caregiver, and other family member run services and supports, as well as the evidence bases demonstrating their effectiveness (see **Appendices Two, Three, Four,** and **Five** for detailed reviews of the histories and evidence bases for each of these four groups). These reviews clearly establish that consumer and family run services and supports are promising practices with an emerging evidence base. Consumer and family run organizations currently operating in Washington State include long-standing consumer run organizations like Thurston County's Capital Clubhouse and Clark County's Consumer Voices are Born, as well as newer groups like the multi-county New Century Empowerment Project; youth run organizations such as the statewide Youth 'N Action program; parent / caregiver run organizations like King County's A Village Project II and Statewide Action for Family Empowerment of Washington network organizations, including A Common Voice for Pierce County, BRIDGES to Parent Voice (Clallam, Kitsap, and Jefferson Counties), Changes Parent Support

Network (King and Snohomish Counties), Spokane's Passages program, and Training Resources in Partnership (Island, San Juan, Skagit, Snohomish, and Whatcom Counties); and family run organizations such as the 23 National Alliance on Mental Illness (NAMI) affiliates statewide. The Mental Health Planning and Advisory Council's recommendations prioritized consumer and family run organizations in Washington's Fiscal Year 2009 plan submitted to the Substance Abuse and Mental Health Services Administration. Such services and supports can achieve significant outcomes, and their success is demonstrated daily in the lives of people with mental illness and their families, as well as within the published literature.

However, the reviews in the appendices also make clear that the implementation of consumer and family run services and supports in Washington State should not be limited to one or even a handful of models or service types. While familiar approaches like peer support are important, what is most important is the responsiveness of consumer and family run services and supports to the priorities and needs of the people who use them to support their own recovery and resilience within a specific community. Because of this, the Work Group adopted the following principle as the basis of our proposed plan for implementing consumer and family run services and supports in Washington State: ***Washington State needs a broader and diverse array of consumer and family run organizations to develop and provide an ever-expanding array of services and supports grounded in the priorities of the consumers and family members that live in the communities where those programs operate.***

> *My parent partner came to my house many times during late night hours to assist me when my child was in a melt down, and was being abusive to me and his my other children. I learned so much about how to handle times of melt down, to set boundaries, and when to keep my mouth shut. Due to the assistance of my partner, I cancelled my CLIP bed for him, as I now know how to respond to the chaos.*

Members of the Work Group took the lead in developing a broad overview of the types of services and supports that should be available. The summary began with an initial list developed during the first Work Group meeting in late April, then incorporated a review of the input of consumers and family members provided in previous initiatives such as the 2007 System Transformation Initiative, the 2007 and 2008 forums related to SHB 1088, and additional data from youth reviewed in collaboration with Youth N' Action. This information concluded that possible supports include mutual support, community building, a wide array of specific services and supports, and advocacy. Please see **Appendix Six** for examples of the types of services and supports that could be provided.

Multiple Levels of Development

As with every type of business, consumer and family run organizations have a mixed history of success nationally and in Washington State. When defining "success," it is important to recognize the multiple levels of development needed to successfully implement any organization, including consumer and family run organizations. Such recognition allows for enhanced support of the development of consumer and family run organizations by identifying the funding and resource options, as well as technical assistance needs, that fit with each stage of development. The Work Group used the following framework to guide our development of funding, technical assistance, and certification recommendations in the report.

Developmental Framework for Consumer and Family Run Organizations

Pre-Implementation Stages - Interviews with national key informants identified a range of activities critical to the establishment of consumer and family run organizations across the country.

Implementation Stages - The field review draft of the COSP EBP Kit defines three steps in implementation which seem to apply to both consumer and family run organizations after they have started-up.

Independence Option - Many consumer or family run organizations may choose to operate without official state recognition, and there is a strong history of successful independent consumer and family run organizations. As independent organizations, they are subject to all city, county and state laws. They may choose to affiliate with similar organizations, but they would not seek certification by state government. Independent groups, agencies or affiliate organizations may choose to remain at this level indefinitely. Also, independent organizations may in the future decide to become certified.

Discovery - Identify people and resources to lead, organize, and participate in the organization.

Leadership Development - Identify, train, and support consumer and family leaders to plan and start up organizations.

Organization Planning/Start-Up - Basic business and organizational planning to prepare and establish the organization.

Establishment - Putting in place basic operational and management practices and begin to provide initial supports.

Business Development - Expand organizational management skills and range of supports.

Enhancement - Expand both organizational and service delivery capacity.

Pre-certification Preparation - Determine if certification fits with organizational mission, then assess readiness.

Formal Certification - Once certified, access to expanded funding and recognition can build sustainability.

Additional Certification / Licensure - Consumer / family run organizations can also become clubhouses or CMHAs.

Certification Options - Implementation of State certification standards for Consumer and Family Run Organizations would offer a new set of alternatives for those whose mission and capacity fits these options. In addition, some may choose to also seek certification as clubhouses or licensure as community mental health agencies. Some may in the future choose to return to independent status.

Section 3 – Development of the Continuum of Funding and Resource Options Needed for Implementation

As consumer and family run organizations progress through each stage of development, funding is required that fits the services and supports to be delivered. This will need to come from a continuum of sources over time, recognizing that the diversity and breadth of funding and other resources that an organization obtains is itself a measure of health and sustainability. While some funding sources require more capacity and administrative infrastructure than others, all require sound fiscal management and accountability practices. Because of this, technical assistance should be available to consumer and family run organizations and their funding sources to support their development as strong and viable organizations at their stage of development.

For example, in the Pre-Implementation Stages there is a need to fund both targeted technical assistance to support the formation of organizations and flexible seed money to support start-up. State general funding through MHD and federal Mental Health Block Grant funding are particularly important at this stage, as are local funds and resources. During the Implementation Stages, continued funding of technical assistance through state and federal sources is needed, but organizations can also expand their range and tap into funding that requires an established organizational track record, including local and state foundation grants, federal grants, and RSN-level funds to provide informal peer supports. Diverse local supports can also be critical, including membership dues, fund raising, in kind supports from community organizations, volunteers, and grassroots profit-making ventures. A smaller subset of funding options would be available only to those organizations that progress to the Certification Stages. This report focuses in later chapters on access to Medicaid funds (for which certification will be essential), but certification can also pave the way to enhanced support from all of the funding sources already noted, as well as provide the external sanction to facilitate funding from a broad array of state and federal agencies. See **Appendix Seven** for an overview of various funding sources available to consumer and family run organizations.

In order to be successful, specific resources will need to be committed to the formation, support and ongoing funding of consumer and family run organizations, as well as the services and supports they provide. Funding will likely require a mix of sources across agencies, as well as a mix of new and redirected funding. Action is needed in three areas:

- The dedication of specific resources to fund **technical assistance to develop consumer and family run organizations across the state** at multiple levels of development, including dedicated funding for both the start-up of new organizations in communities that currently lack them and the enhancement of existing organizations to expand and sustain their array of supports;
- The development of **regulatory requirements to certify consumer and family run organizations** to allow those organizations ready to seek expanded state and Medicaid funding to do so; and
- Implementation of **a pilot program to fund the provision of services and supports** by consumer and family run organizations over time and evaluate their benefits, costs, and potential cost-savings to the broader system.

Such a pilot program would allow the state to take concrete steps to strengthen the network of consumer and family run organizations statewide, as well as facilitate the thoughtful expansion of safety nets in key communities to include enhanced consumer and family run services within an integrated network of community supports. **Since it was beyond the scope of this report to carry out the detailed cost analyses and actuarial projections needed to recommend specific funding amounts, the Work Group recommends that MHD carry out such analysis as part of its implementation of the recommendations of this report, working in partnership with consumer and family leaders to determine funding levels.**
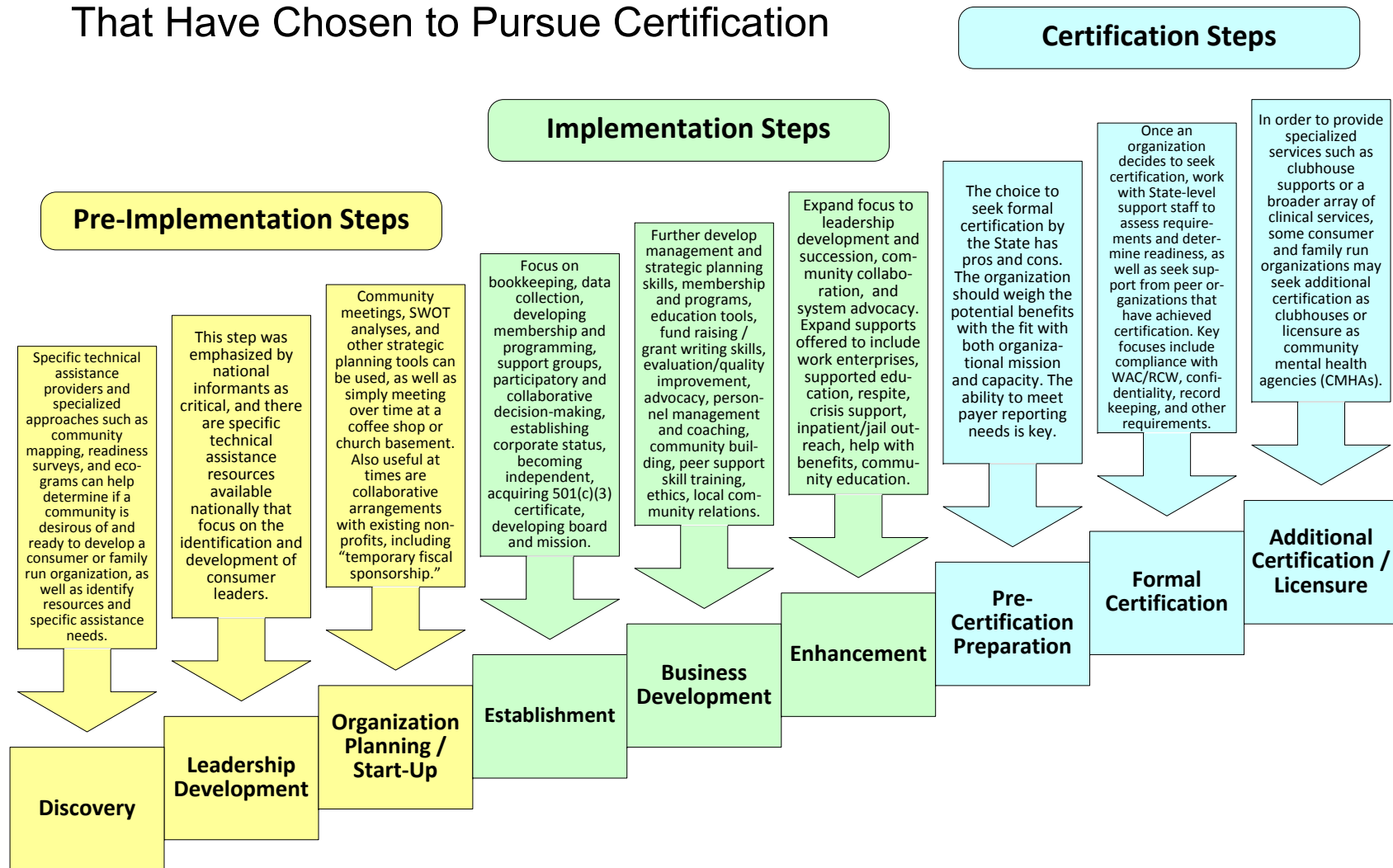
Consumer and family run organizations will need to pursue multiple and diverse funding sources that fit with their organizational mission and meet the needs of the local community. Each funding source is unique with changing priorities and requirements. Therefore, it is imperative that consumer and family run organizations maintain their organizational health and develop financial support for their local missions by anticipating changes and remaining relevant to community needs. There is a critical link between locally-determined priority-setting (i.e., what do local groups of consumers, youth, or family members want to do?) and the funding chosen. The experience of past failed efforts to start consumer and family run organizations in Washington illustrates that in some cases there was not sufficient attention to diversified funding and an incremental approach that built on local efforts. Large external grants that bring a fast infusion of funds can be as challenging as they are supportive when they are not tied to a demonstrated organizational capacity to develop resources and leadership locally. Thoughtful planning and an incremental approach can sometimes take longer and seem more conservative, but it is often the healthiest approach for a handful of committed people to take small steps together.

Section 4 – Technical Assistance to Develop and Assist Consumer and Family Run Organizations

Technical assistance for consumer and family run programs has been identified by researchers and advocates as a needed component to organize and implement these services. The importance of initial, developmental, and ongoing technical assistance is essential to help these organizations secure funding and provide services and supports to consumers and families. To help consumer and family run organizations develop the organizational capacity needed to deliver and account for Medicaid funded services, technical assistance is needed at each of the developmental levels noted in Section 2: pre-implementation to discover resources, develop leaders, plan the organization and start-up; post-implementation to establish the organization, develop needed business processes, and enhance competencies; and during the certification process necessary to progress to eventual credentialing as a Medicaid provider. Specialized technical assistance for consumer and family run organizations is necessary at each level as technical assistance experts transfer knowledge and skills to locally-based consumer and family organizations. However, underlying all levels of needed technical assistance is the recognition that consumer and family run programs are unique, peer-driven organizations providing needed services and supports as a complement to the broader mental health service system. The figure on the following page summarizes the types of needed technical assistance by developmental level.

Technical Assistance Needs for Organizations That Have Chosen to Pursue Certification

Certification Steps

Implementation Steps

Pre-Implementation Steps

Specific technical assistance providers and specialized approaches such as community mapping, readiness surveys, and eco-grams can help determine if a community is desirous of and ready to develop a consumer or family run organization, as well as identify resources and specific assistance needs.

This step was emphasized by national informants as critical, and there are specific technical assistance resources available nationally that focus on the identification and development of consumer leaders.

Community meetings, SWOT analyses, and other strategic planning tools can be used, as well as simply meeting over time at a coffee shop or church basement. Also useful at times are collaborative arrangements with existing non-profits, including "temporary fiscal sponsorship."

Focus on bookkeeping, data collection, developing membership and programming, support groups, participatory and collaborative decision-making, establishing corporate status, becoming independent, acquiring 501(c)(3) certificate, developing board and mission.

Further develop management and strategic planning skills, membership and programs, education tools, fund raising / grant writing skills, evaluation/quality improvement, advocacy, person-nel management and coaching, community buil-ding, peer support skill training, ethics, local com-munity relations.

Expand focus to leadership development and succession, com-munity collabo-ration, and system advocacy. Expand supports offered to include work enterprises, supported edu-cation, respite, crisis support, inpatient/jail out-reach, help with benefits, commu-nity education.

The choice to seek formal certification by the State has pros and cons. The organization should weigh the potential benefits with the fit with both organiza-tional mission and capacity. The ability to meet payer reporting needs is key.

Once an organization decides to seek certification, work with State-level support staff to assess require-ments and deter-mine readiness, as well as seek sup-port from peer or-ganizations that have achieved certification. Key focuses include compliance with WAC/RCW, confi-dentiality, record keeping, and other requirements.

In order to provide specialized services such as clubhouse supports or a broader array of clinical services, some consumer and family run organizations may seek additional certification as clubhouses or licensure as community mental health agencies (CMHAs).

Discovery

Leadership Development

Organization Planning / Start-Up

Establishment

Business Development

Enhancement

Pre-Certification Preparation

Formal Certification

Additional Certification / Licensure

Consumer-to-consumer and family-to-family technical assistance organizations, as well as organizations supporting a broader range of non-profit organizations, can be found throughout the United States. There are at least five

[NAMI's Family to Family] is an excellent course. In a very short time, my understanding of mental illness has multiplied, my heart has changed, my hope for my child has been restored, and my desire to advocate for the mentally ill has become a reality.

national technical assistance centers funded by the federal government for consumer run organizations and a host of other entities providing technical assistance to family and youth run programs. A table summarizing many of these resources is provided in **Appendix Eight**. A statewide infrastructure to provide such technical assistance should be developed based on the following principles:

- A **statewide infrastructure** to support consumer, youth, and family run services in all stages of development should be established.
- This infrastructure should be run at the **grassroots level**, using the skills and knowledge of consumer, youth, and family groups that already exist in the state.
- Centralized **Technical Assistance Centers** should be developed with the resource capability to provide technical assistance to assist grassroots agencies and organizations and local and state government through information, training and mentoring. The centers would support: (1) consumer run organizations, (2) family run organizations, (3) organizations for youth in transition, (4) other diverse age groups, (5) diverse populations statewide, including urban and rural communities, and (6) local RSNs, providers, and allied services. Technical assistance centers in other states noted in Appendix Eight can serve as models and supports.
- The Technical Assistance Centers should be **consumer / family run**. Ultimately, the statewide infrastructure should include dedicated Centers for consumers, youth, and families, with regional capacity available in both eastern and western Washington. However, initial efforts to develop the capacity should ideally start with dedicated consumer, youth, and family centers.
- The Technical Assistance Centers should have the **capacity to assess needs for technical assistance**, as well as **evaluate the effectiveness of assistance provided** (either independently or in collaboration with evaluation partners). Tracking and evaluation of consumer and family run organizations could also be incorporated.
- The Technical Assistance Centers can be **funded through a variety of state and federal sources** and have some responsibility for securing a portion of their own funding, including the possibility of charging fees for services. However, a core of ongoing state support will be necessary to establish and maintain the Centers for a period of years.
- The role for consumers and families to identify technical assistance needs – both at the local level and centrally through Technical Assistance Centers – should encourage openness and communication. The Centers should have the capacity both to **provide a core set of technical assistance directions, as well as to broker the provision of technical assistance by more specialized sources**. To support this, the Centers should have access to dedicated funds to be jointly allocated by the Centers and the local organizations in need of support.

Section 5 – Recommended Licensing and Certification Requirements

Recommendations for a Continuum of Sanctioning Options

SHB 2654 required the development of "recommendations related to licensing or certification requirements that should be applied to community service agencies." As discussed in the definitions in Section One of this report, the term "Consumer and Family Run Organizations" was selected as an alternative to the term "Community Service Agency." This change in emphasis was made in order to keep the focus of certification efforts primarily on the consumer and family run nature of the organizations this report was charged to support.

The Work Group clearly identified a need for a continuum of sanctioning options, in addition to formal certification. It should be noted that the decision of the Work Group to offer sanctioning options was questioned by some members given that so few consumer and family run organizations exist currently in Washington State. In the words of one Work Group member: "*Consumers are still grappling with leadership development, empowering others, bricks and mortar, financial management, clear articulation of local consumer needs, and the like. Sanctioning and licensing seem to be way down the road.*" Concerns about the "medicalization" of consumer and family run services were also noted. However, the Work Group determined that it was critical for those organizations ready for and desirous of certification to have the opportunity to gain the external recognition needed to meet their goals and gain access to more diversified service delivery options and funding.

The broader term "sanctioning" recognizes that implementation of a wide range of consumer and family run organizations in Washington will require multiple means for giving effective and authoritative approval or consent. A sanctioning continuum recognizes that consumer and family run organizations operate independently and choose how to be officially recognized. Sanctioning options – whether registering, certifying, licensing, or credentialing – do not assure that a consumer and family run organization ultimately contracts with any entity. It does demonstrate, however, that the consumer and family run organization has the organizational structure, business practices, and quality recovery- and resiliency-oriented services that merit consideration in a competitive process.

An overarching status that could apply to any of the levels of sanctioning noted below are those organizations that are allied, affiliated with or part of a national organization. These organizations have standing accredited them by their national organization, but may also choose how and to what degree to be sanctioned at the state or local level.

Three levels of state and local recognition or sanctioning related to consumer and family run services were identified:

- **Independence** – This first level is informal and by its nature not amenable to specific state-level regulation. An independent consumer or family run organization chooses to operate without official state recognition. As independent organizations, they are subject to all city, county and state laws. They may choose to affiliate with similar organizations, but they would not seek certification by state government. Independent groups, agencies or affiliate organizations may choose to remain at this level indefinitely. Independent organizations

may choose to be recognized at the local or state level by listing as a local mental health resource.

▪ **Formal Certification as Consumer and Family Run Organizations** – This level applies to organizations that choose to become a certified consumer and family run organization, a certification sanctioned by the MHD. This would be similar to the current clubhouse certification requirements (WAC 388-865-0700 / RCW 71.24.035) in their structure and oversight. Initial applicants that can show that they have all organizational structures and written policies in place, but have yet to demonstrate that they meet minimum standards, may be granted initial certification for up to one year. Successful completion of an on-site certification review is required prior to the expiration of initial certification to demonstrate that the organization has all necessary organizational structures and written policies in place, as well as a performance history to demonstrate that they meet minimum standards. Technical assistance for achieving and maintaining certification will be available to consumer and family run organizations, as well as RSNs seeking to develop such capacity in their area. This certification would not be mutually exclusive with other types of certification and licensure overseen by MHD. For example, a certified consumer run organization may want to also be certified as a clubhouse (for example, Capital Clubhouse in Olympia is consumer run) or licensed as a community mental health agency (for example, the Passages program in Spokane).

▪ **Certified Consumer and Family Run Organizations credentialed to provide Medicaid services** – Those Certified Consumer and Family Run Organizations seeking to provide Medicaid billable services can become credentialed by their RSN to do so, using their state certification, pending modification to the 1915(b) Waiver as described in the next section of this report. The RSN would need to ensure that the consumer and family run organization seeking Medicaid credentialing meets the qualifications in the State Plan for each Medicaid service provided. Technical assistance for achieving and maintaining credentialing would need to be available.

Recommendation: Implement, Pilot and Finalize Certification Requirements for Consumer and Family Run Services

Given the potential benefits identified for services and supports delivered by consumer and family run organizations, the Work Group recommends that MHD develop certification requirements to formally sanction these organizations. In order to ensure the successful transition of those organizations currently ready for such certification, as well as documentation of the costs and benefits of the certification standards and technical assistance resources developed, it is recommended that MHD implement and refine the standards through a three step process:

▪ **Develop Certification Requirements –** Building on the successful structure and approach developed for MHD's clubhouse certification requirements, MHD should partner with consumers and family members to develop certification requirements for consumer and family run organizations for implementation by July 1, 2009.

▪ **Support Implementation through Pilots –** In order to ensure the provision of adequate technical assistance, coordinate with existing services, and evaluate the effectiveness of the organizational development process, fund and implement a pilot of at least two consumer run and two family run organizations to establish their initial certification under the new requirements by January 1, 2010.

- **Refine Requirements Through Evaluation –** MHD should also fund an evaluation carried out by an evaluation team consisting of qualified researchers and consumer and family member evaluation staff. This team would monitor and assess the effectiveness of the certification requirements and technical assistance in supporting the development of the pilot sites, including the potential for replicability. The goal of the evaluation would be to inform the ongoing refinement of the certification requirements so that finalized certification requirements can be in place by July 1, 2011. To the extent that the evaluation examines the effectiveness of the consumer and family run services provided, the evaluation should also examine the effectiveness of comparable services delivered by community mental health agencies, including peer support, individual treatment, and group treatment interventions.

Potential Sources for Consumer and Family Run Organization Certification Requirements

Multiple sources should be used to inform the development of Certification Standards. Among those sources recommended for consideration are the following:

- **Framework of MHD Clubhouse Requirements** – The current clubhouse requirements define both program components (WAC 388-865-0710) and management/operational requirements (WAC 388-865-0715). While the program component requirements are not applicable to consumer and family run organizations given the differential service mission of the two types of organizations, the management/operational requirements are directly applicable.
- **Sources for Program Component Requirements –** There are many sources describing the critical aspects of consumer and family run programs, and many are represented in the four appendices that review the histories and evidence bases for these services. One attempt to identify the "common ingredients" to consumer run services was the Fidelity Assessment/Common Ingredients Tool (FACIT). It was initially developed by the federal Center for Mental Health Services to assess to what extent consumer-operated services shared common elements, and it has been adopted as a quality measurement tool as part of the draft field manual of Consumer Operated Service Program Evidence Based Practice (COSP EBP) KIT.[1] While developed for consumers, many principles seemed applicable to families; family members from the Work Group reviewed these standards and noted that, with appropriate modification, all of the standards could apply well to family run organizations. We also reviewed a program logic model building tool developed for families by the Federation of Families for Children's Mental Health (Igniting a New Vision: The Developing Journey of a Family Run Organization) and a consumer survey for use with a wide variety of public health care entities, the Experience of Care and Health Outcomes (ECHO) Survey. Other potential sources not reviewed because of their proprietary nature include the Commission on Accreditation of Rehabilitation Facilities (CARF) requirements for consumer-run (CR) programs. The Work Group recommends that MHD draw on all of these requirements (including those not reviewed in this report, like CARF), keeping an eye towards new and emerging approaches as they develop requirements.

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[1] Center for Mental Health Services (CMHS). (November, 2007). <u>Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft</u>. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.

- **Medicaid Requirements** – To the extent that the consumer or family run organization delivers Medicaid funded services, the requirements from Washington's Medicaid State Plan for those services will need to be included. Arizona's Community Service Agency certification, which focuses on both agency certification and staff qualifications for each Medicaid service provided, can be considered as a model for Washington. Washington would need to ensure that staff in consumer and family run organization with Medicaid Certification met the qualifications in the State Plan for each Medicaid service provided.

The sources just noted can provide more detail on potential standards. However they are examples only and are not recommendations for any particular standard to be adopted. To make specific recommendations would be beyond the scope of the Work Group's mandate. There were questions within the Work Group about whether the tools that form the basis for some of the examples sufficiently involved consumers in their development or captured the uniqueness of the full range of consumer run programs. Nevertheless, the Work Group determined that it was important to offer some guidance in order to expedite the development of certification requirements for those consumer and family run organizations interested in taking on this level of external scrutiny and the opportunities it affords.

Section 6 – Amendment of the Mental Health Waiver and State Plan

SHB2654 specifically directed DSHS to address in this report "Amendment of the mental health waiver and state plan related to utilization of Medicaid for financing of services . . ." That requirement is addressed, while keeping in mind that the development of consumer and family run services and supports in Washington will require a much broader array of funding than Medicaid. Medicaid funding, while an important source of revenue, may only be available in the short term for a relatively small number of currently established consumer and family run organizations ready to meet its rigorous accountability and fiscal reporting requirements. Medicaid covers medical services only, so only a subset of the services and supports discussed in Section Two (and detailed further in Appendices Two through Five) can be funded through Medicaid. Furthermore, the only medical services that can be delivered by peers without the direct supervision of a mental health professional within Washington's Medicaid program currently are peer support services. While the involvement of a mental health professional is required, the language in the State Plan is broader than for other modalities (emphasis added):

> 13) <u>Peer Support:</u> Services provided by peer counselors to Medicaid enrolled individuals **under the consultation, facilitation or supervision of a mental health professional who understands rehabilitation and recovery**. This service provides scheduled activities that promote socialization, recovery, self-advocacy, development of natural supports, and maintenance of community living skills. Consumers actively participate in decision-making and the operation of the programmatic supports. (Attachment 3.1-A, page 6-16)

This language allows for a consultative relationship between the peer support counselor and the mental health professional involved in the consumer's care, and this is supported in the requirements defining peer support services (WAC 388-865-0453) and peer counselor certification (WAC 388-865-0107), neither of which stipulate supervision requirements beyond

those in the State Plan. All other State Plan modalities require either direct delivery by a mental health professional or direct supervision by a mental health professional of the practitioner delivering the service. The State Plan defines staff supervision as "monitoring the administrative, clinical or clerical work performance of staff, students, interns, volunteers or contracted employees by persons with the authority to direct employment activities and require change"

> *I was diagnosed with a disorder in the Army and was shipped back to Ft. Lewis. I was in total denial as far as I believe. I was honorably discharged. I spent a lot of time in the V.A. system. I came to the clubhouse in 1990. It was not a great place to be. But surely it turned around to be the best place to come. I needed the interaction and small tasks to do. I have grown strong and in recovery somewhat better then I was a long time ago.*

(Attachment 3.1-A, page 6-12), thereby requiring the mental health professional to be employed by the same organization as the peer support specialist and to have authority over that person. While the State Plan does not specifically define "consultation" or "facilitation," it later uses the term "consultation" as part of the definition of Special Population Evaluation and specifies that it can involve a staff member "employed by another CMHA" (Attachment 3.1-A, page 6-17). The broader language defined for peer support allows for a more collaborative relationship and offers flexibility for certified consumer and family run organizations to coordinate services under the consultation of a mental health professional, rather than have to employ a mental health professional in a position of authority over the certified peer counselor.

In addition to peer support, two other Medicaid services available under the 1915(b) waiver as (b)(3) services were also identified as important to include in the potential service array for consumer and family run organizations: respite and supported employment. These services currently require direct supervision by a mental health professional. In order to allow these services to be delivered by consumer and family run organizations without requiring these organizations to employ or contract with mental health professionals, the waiver would need to be amended to allow for "consultation" by a mental health professional for these services, similar to the current arrangement allowed in the State Plan for peer support. As (b)(3) services, requirements for respite and supported employment could be modified without introducing a State Plan Amendment.

In light of this, the review of the Medicaid State Plan and 1915(b) Waiver centered on their ability to support the delivery of peer support, respite, and supported employment by consumer and family run organizations. That review was based on the analysis of these documents carried out in 2007 under the MHD's Statewide Transformation Initiative (STI). Based on our review, the Work Group makes the following two recommendations:

1. Do not amend the Medicaid State Plan. The 2007 STI Benefit Package Design report accepted by the Mental Health Division concluded that Washington's Medicaid State Plan is sufficiently sound to support the provision of peer support by consumer and family run organizations.[2] The Work Group considered again these findings and did not identify any reason to take an alternative stance.

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[2] TriWest Group. (July, 2007). Previously cited.

2. Add language to the 1915(b) Waiver recognizing properly credentialed Certified Consumer and Family Run Organizations as eligible providers of Peer Support and select (b)(3) services. The current 1915(b) Waiver defines the organizations that can participate in RSN networks to provide Medicaid services. Historically, the 1915(b) Waiver has identified full service, licensed community mental health agencies (CMHAs) as the primary agencies comprising the provider networks of the State's Prepaid Inpatient Health Plans (PIHPs), the technical term that CMS uses to describe the Medicaid managed care plans administered in Washington by the RSNs. The primary language defining this role in the Waiver is concise and clear: "The PIHP contracts with licensed CMHAs for the provision of mental health services. The MHD is the licensor of CMHAs . . ."

In the most recent 1915(b) Waiver, MHD added language recognizing its newly implemented Clubhouse certification standards (WAC 388-865-0700 thru 388-865-0725). As with other language in the 1915(b) Waiver, the recognition is quite brief: "Clubhouses must be certified by the MHD beginning in 2008."

States with 1915(b) Waivers have broad authority to allow their PIHPs to allow the delivery of covered Medicaid services by providers that meet the qualifications of the Medicaid State Plan as cost-effective alternatives. By adding recognition of certified Clubhouses to the current 1915(b) Waiver,

> *I had been fighting the system trying to get the help that my son needed. . . . Moreover, the greatest benefit to my family and myself amongst several was my parent partner. She was a real person to me, someone that has been working through the system herself. . . She sat beside me and helped me out with words I could not express myself because of fear. . . She stood beside me when I had to go to the school and get my son at recess (he had been denied recess most of the year). . . She also stepped up to the plate when we had to go through and implement a crisis plan that would be good for my family.*

MHD clarified the requirements to deliver (b)(3) Clubhouse services under the Waiver. MHD could add comparable language recognizing Certified Consumer and Family Run Organizations as providers of Peer Support Services, as long as their staff providing these services meet the requirements stipulated in the Medicaid State Plan. These include:

- Certification as a Peer Counselor;
- Services must be noted in the consumer's Individualized Service Plan;
- Monthly progress notes with evidence of consultation, facilitation, or supervision of services by a mental health professional;
- Daily logs identifying Medicaid eligibility for any services in drop-in center;
- No more than four (4) hours a day per consumer; and
- Ratio must be at least one (1) Peer Counselor per 20 Peers.

Language can also be added to the (b)(3) definitions of respite and supported employment to allow them to be delivered with "consultation" by a mental health professional if the service is delivered by a consumer or family run organization. Combined with language allowing the provision of such services by a consumer or family run organization, such a change would be analogous to the change made in the last waiver recognizing clubhouse certification.

Section 7 – Recommendation to Assure that Consumer and Family Run Services are Integrated with Other Treatment Services

The Work Group looked closely at the need to integrate the services and supports provided by consumer and family run organizations with those provided by other treatment providers, including CMHAs, clubhouses, inpatient facilities, state hospitals, and allied service systems. One critical support for this at the individual consumer level is the importance of the inclusion of consumer and family run services in the Individual Service Plans of consumers and family members involved in formal service delivery from these agencies.

The mechanisms of successful service coordination are well established. Above all, their success centers on recognition of the lead role of the consumer in guiding treatment in support of their own recovery and resilience. Processes to support this have been well described in past reports, including the guidance of SHB 1088 forums held in 2007 and 2008 related to children's services and the Statewide Transformation Initiative related to evidence based approaches to service coordination. Supports are also needed to help the key agents in this endeavor – consumers, youth, parents and caregivers, other family members, consumer and family run organizations, Clubhouses, CMHAs, RSNs, other providers – come together in collaborative support of the recovery and resilience of the people they serve. The role of MHD in leading and supporting this coordination is essential. In addition, the Work Group recognized the need to support RSNs and CMHAs through technical assistance (TA) in the following areas:

- **Helping RSNs and CMHAs be recovery and resilience oriented** – TA is still needed to help some agency staff develop knowledge, skills, and attitudes more congruent with recovery. The system needs to adopt recovery at a deep and detailed level, so that policies reflect the principles of recovery and resilience and agencies have consumer and family input in their governance boards and advisory/planning committee/councils.
- **Education about the value of consumer and family run services** – There needs to be focused efforts to help some CMHAs see the "value added" through partnerships with consumer and family run service organizations. In some cases, RSNs may need to require CMHAs to develop agreements with consumer and family run service organizations to assure integration and inclusion of their supports in Individual Service Plans.
- **Training in effective collaboration** – Requirements for collaboration are well established in the WAC and in legislation such as E2SHB 1290 (which increased oversight and monitoring of RSN managed care operations), but too often in systems everywhere it does not happen. While specific contract requirements can help, ultimately collaboration is about building relationships. TA is essential, preferably joint TA involving diverse providers (CMHAs, Clubhouse, consumer and family run organizations).
- **Engage agencies with an established track record** – TA and mentoring can be supported by partnering with established organizations already working well together who can share their experiences, perspectives, and approaches with others.
- **Establishing consumer and family run services as standard treatment expectations** – Partnering with consumer and family run service organizations is too often seen as an "enhancement" to standard mental health services. It should be part of standard treatment expectations, and key to this is the Individual Services Plan. While not all consumers will choose these supports, their consideration should be a standard in every system of care in the State.

Appendix One: Sources Used to Develop the Definitions in This Report

In order to promote the broadest possible implementation of consumer and family run services, as well as to develop standards to support that development, it was first necessary to develop some guiding definitions. As discussed in the body of the report, the Work Group took its primary guidance from the text of SHB 2654, which focuses on both consumers and families, adding a specific emphasis on youth in transition given their importance as a distinct subgroup among the broader array of consumers.

Once this was decided, we examined closely the current Washington Administrative Code (WAC) definition of **"consumer"** (WAC 388-865-0150), which defined the term to mean:

> "A person who has applied for, is eligible for or who has received mental health services. For a child, under the age of thirteen, or for a child age thirteen or older whose parents or legal guardians are involved in the treatment plan, the definition of consumer includes parents or legal guardians."

This definition combines consumers who themselves apply for, are eligible for, or receive mental health services with the parents and guardians of child-age consumers. This definition does not adequately differentiate between people who would come together to form a consumer run organization (consumers who themselves apply for, are eligible for, or receive mental health services) and people who would come together to form one subset of family run organizations (parents and guardians of child-age consumers). Work Group members noted that certain federal grants specific to consumer and family run organizations had been inaccessible because of this lack of differentiation. Furthermore, the WAC definition does not address the status of family members of adults, though they are recognized in Regional Support Network (RSN) contract language.

Because of this, the Work Group recommended that a broad fabric of consumer and family run organizations be supported, consistent with SHB 2654 and the inclusive nature of WAC 388-865-0150, but that the three primary subgroups woven together to define that fabric be differentiated: consumers, parents/guardians of child consumers, and adult family members.

Definitions of Consumer and Family Run Organizations. To develop these definitions, we reviewed multiple sources.

One important defining feature of consumer and family run organizations is that they are controlled by consumers and families. The federal Substance Abuse and Mental Health Services Agency (SAMHSA) has developed definitions of consumer-controlled and family-controlled organizations, as follows:

- **Consumer-controlled:** Refers to an organization that is controlled and managed by mental health consumers and is dedicated to transformation of the mental healthcare system to be consumer and family driven. A consumer-controlled organization must have a board of directors comprised of more than 50% consumers. (2007, SAMHSA, SM-07-002, Appendix C – Glossary)

- **Family-controlled:** A family-controlled organization is an organization that has a board of directors made up of more than 50% family members, who have primary daily responsibility for the raising of a child, youth, adolescent or young adult with a serious emotional disturbance up to age 18, or 21 if the adolescent is being served by an Individual Education Plan (IEP), or up to age 26 if the young adult is being served by an Individual Service Plan in transition to the adult mental health system. (2007, SAMHSA, SM-07-001, page 7)

The Work Group also reviewed broader definitions of consumer and family run organizations, drawing particularly on the November 2007 Field Review Draft of SAMHSA's Consumer Operated Services (COSP) Evidence-Based Practices KIT, which defines a "consumer-operated services program (COSP) as a peer-run service program that is **owned, administratively controlled,** and **operated** by mental health consumers and **emphasizes self-help as its operational approach.** The definition stresses five key elements:
- **Independent:** The organization is controlled and operated by consumers,
- **Autonomous:** Decisions about governance, fiscal, personnel, policy, operation are made by the COSP,
- **Accountable:** Responsibility for decisions rests with the COSP,
- **Consumer controlled:** At least 51% of the governance board are consumers, and
- **Peer workers:** Staff and management have received mental health services."[3]

The Work Group saw the outlines of this definition as incorporating the values of the System of Care movement promoting family and youth involvement (Pires, 2002),[4] which focus on:
- Policy: Ensuring at least a 51% vote by family members on governing bodies, as well as oversight of purchasing and contracts,
- Management: Involvement of family members in the quality improvement process, as evaluators of performance, and as trainers, and
- Services: Direct service delivery by family members as family support workers, care managers, peer mentors, and system navigators, with an emphasis on behavior rather than diagnosis.

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[3] Center for Mental Health Services (CMHS). (November, 2007). Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.

[4] Pires, S.A. (Spring, 2002). Building Systems of Care: A Primer. National Technical Assistance Center for Children's Mental Health, Center for Children and Mental Health Policy, Georgetown University Child Development Center: Washington, DC. Pp: 74.

Appendix Two: The History and Evidence Base of Consumer Run Services and Supports

Three primary documents contributed to this appendix: "The Rise of Consumerism" by Laura Van Tosh, Ruth O. Ralph, and Jean Campbell,[5] "Consumer-Operated Self-Help Programs: A Technical Report" by Laura Van Tosh and Paolo del Vecchio,[6] and "Consumer-Operated Services Programs: The Evidence" (from the field review draft of the COSP manual),[7] to be published by the Substance Abuse and Mental Health Services Administration (SAMHSA).

History of the Mental Health Consumer Movement

According to Van Tosh, Ralph and Campbell (1999), "the mental health consumer movement began when people who had been psychiatrically hospitalized and/or their families protested against the inhuman treatment received." Examples of some of the earliest efforts of the mental health consumer movement included The Alleged Lunatic's Friend Society, established in England in 1845; the Anti-Insane Asylum Society, founded by Elizabeth Packard in the United States shortly after the Civil War; Elizabeth Stone's work around the same time in Massachusetts; and Clifford Beers' writings and involvement in founding the National Committee for Mental Hygiene in the early 1900's. The draft COSP manual notes that "most of these accounts reached beyond individual concerns and mobilized former patients, the general public, legislatures, policy makers and even the professions to improve services for all people diagnosed with mental disorders" (pg. 4).

In the late 1940s, a self-help group called We Are Not Alone (WANA) was formed by patients in Rockland State Hospital in New York. After discharge from the hospital, this group continued to meet, attracted volunteers and eventually evolved into Fountain House, the founder of the clubhouse movement. In addition, the draft COSP manual notes that in 1937, a group of ex-patients in Chicago formed an organization at the suggestion of Dr. A. A. Low of the Illinois Psychiatric Institute. This group, Recovery, Inc., was identified as an important development in self-help, even if the members chose to follow a psychiatrist instead of one of their own.

Van Tosh, Ralph and Campbell cited Chamberlin's (1997) observation that the mental health consumer movement began its modern form in the early 1970s without knowledge of any of these historical roots. Van Tosh, Ralph and Campbell quote Frese and Davis (1997):

> "… individuals in different parts of the country who had been hospitalized for mental illness began to realize that former patients, like members of other marginalized groups, had been legally denied basic rights. They saw that they, too, were regularly described

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[5] Van Tosh, L., Ralph, R. & Campbell, J. (1999). The rise of consumerism. A Contribution to the Surgeon General's Report on Mental Health.

[6] Van Tosh, L. and del Vecchio, P. (2001). Consumer-operated self-help programs: a technical report. Rockville, MD: U.S. Center for Mental Health Services.

[7] Center for Mental Health Services (November, 2007). <u>Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft: The Evidence</u>. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.

by insulting and devaluating language, and that society discriminated against people who were stigmatized as *the mentally ill*. Sensing the possibility for change, former mental patients began to gather periodically to plan strategies to regain their rights and renounce the imposed role of powerless victims (pp. 243-244)" (pp. 1-2).

Van Tosh, Ralph and Campbell go on to note that early groups, such as the "Alliance for the Liberation of Mental Patients", "The Insane Liberation Front", and "Project Release" took a decidedly militant viewpoint against psychiatry and the established mental health system, which involuntarily committed individuals to psychiatric hospitalization. The draft COSP manual described attempts in the late 1960s of ex-patients joining with radical therapist collectives, only to break away and form separatist movements. This tension between collaboration with professionals and forming separate alternatives has been the legacy of peer support and "remains a creative tension," according to the draft COSP manual. Van Tosh, Ralph and Campbell cite Furlong-Norman (1988) in observing that these groups "sustained membership by providing: peer support, education about services in the community and about the problems consumers were facing, and advocacy to help members access services as well as to change an often oppressive system" (pg. 2).

The Roots of the Mental Health Self-Help Movement

The draft COSP manual notes that the modern self-help movement began during the Depression with the development of Alcoholics Anonymous, which inspired the broader self-help movement to grow to approximately 500,000 groups with over 7.5 million members in the United States. Van Tosh, Ralph and Campbell reported that during the late 1960s and early 1970s, small groups of mental health consumers began organizing in the larger East and West Coast cities, inspired by the increasing popularity and momentum of self-help and other movements (e.g., civil rights, women's rights, etc.), and in response to deinstitutionalization and a greater awareness through media exposure of the abuses that consumers experienced. The authors explain:

> "The movement toward the development of alternative, consumer run (self-help) services began with groups of ex-patients who began to share their stories of demoralization by the mental health system, particularly in psychiatric hospitals, and found that (1) their stories had many similarities, (2) they were angry about these debilitating experiences, and wanted to share this anger, and (3) they wanted to share emotional support with and from others (Chamberlin, 1978)" (pg. 2).

When consumers entered communities, they often experienced loneliness, stigmatization, and lack of access to resources. Examples of determined and successful self-help efforts cited by Van Tosh, Ralph and Campbell include Vancouver's Mental Patients' Association, which developed a seven-day a week drop-in center and five cooperative residences; New York City's Mental Patients' Liberation Project, which wrote a Mental Patients' Bill of Rights shortly after formation of the group; and Boston's Mental Patients' Liberation Front (MPLF), which, led by a small group of its members, published *Your Rights as a Mental Patient in Massachusetts*, "…a 56 page document that included laws concerning commitment, voluntary and involuntary hospitalization, patients' civil rights and treatment, and a bill of rights similar to the one developed in New York City (Chamberlin, 1978)" (pg. 3).

The number and types of consumer-run self-help groups grew over time and a more moderate viewpoint began to be represented. Van Tosh, Ralph and Campbell note that groups such as Emotions Anonymous, GROW and Recovery, Inc. focused more on peer support and far less on advocacy; some groups even welcoming the involvement of professionals in their activities (Kaufman and Freund, 1988; Emerick, 1990; Roberts and Rappaport, 1989). In 1979 the National Alliance for the Mentally Ill (NAMI) was founded primarily by and for the families of individuals with serious mental illness. A subgroup for consumers – the NAMI Consumer Council – was formed in 1985 under the name "NAMI Client Council" (Culwell, 1992; Frese & Davis, 1997). Government agencies and some professionals also began to recognize consumer-run organizations, as noted in the draft COSP manual. For example, the National Institute of Mental Health (NIMH) launched the Community Support Program (CSP) in 1977 to focus on the needs of persons with long-term mental illness.

Communication Among Consumers

Van Tosh, Ralph and Campbell report that, with the initial publication in 1972 of the Madness Network News, and the establishment of the Conference on Human Rights and Against Psychiatric Oppression, which met from 1973 through 1985, voices of early consumer groups began to be heard. In 1976, the President's Commission on Mental Health acknowledged these voices, reporting that "groups composed of individuals with mental or emotional problems are being formed all over the United States" (President's Commission on Mental Health, 1978, pp 14-15) (pg. 4). But it was the publication of On Our Own by Judi Chamberlin in 1978, a personal account of her experience in the mental health system, that marked a milestone in the history of the consumer movement and catalyzed many consumers' involvement in the movement.

The draft COSP manual notes that much of the history of peer support has been passed on through oral histories and woven together from bits and fragments, such as artifacts left in patients' suitcases and found a century later by ex-patients; oral history projects; ex-patient publications; patient comments in clinical records; and ex-patient radio broadcasts. The story of Jenni Fulgham is one example of consumer oral history. In 1947, "Miss Jenni" was admitted to the racially segregated Central State Hospital in Petersburg, Virginia with a diagnosis of paranoid schizophrenia. After being discharged, she worked for the phone company in New York City for 20 years. "Miss Jenni" went on to visit and encourage patients at the city's mental institutions, eventually establishing the Zuni Federation for Mental Health, a three acre, no-cost retreat in Virginia for former patients.

A key development in communication among consumers noted by Van Tosh, Ralph and Campbell was the first national conference of consumers – "Alternatives 85" – funded by the National Institute of Mental Health / Community Support Program and held in Baltimore, Maryland in 1985. These conferences continue to be held and have grown in size, attracting participants from across the United States and a number of foreign countries. Planned by consumers and drawing on skills from national and local consumer organizations, these conferences provide technical assistance and opportunities for networking and information exchange (Acker, 1990; Twedt, 1990).

In addition to the sources summarized above, Van Tosh, Ralph and Campbell note that other methods of communication utilized by consumer groups include newsletters, conference calls, listserv groups and websites.

Impact of the Consumer Movement

The consumer movement has opened doors for consumer involvement on a systems level, note Van Tosh, Ralph and Campbell, including all aspects of planning, delivery, and evaluation of mental health services, as well as in the protection of individual rights. Consumer involvement helped pass Public Law 102-321 (formerly P.L. 99-660), which established mental health planning councils in every State, and supported the development of Protection and Advocacy agencies for patients' rights in every State (Chamberlin and Rogers, 1990). Both of these laws require substantive consumer involvement in planning and implementing mandated activities. In 1990, consumers organized for the cause of empowerment, using the motto "Nothing About Us Without Us," as noted in the COSP manual (Chamberlin, 1997).The consumer movement also influenced increases in the utilization of consumers as employees in the traditional mental health system and other areas (Specht, 1988; U.S. Department of Education, 1990; Schlageter, 1990; Interagency Council on the Homeless, 1991).

Van Tosh, Ralph and Campbell note that the establishment of Offices of Consumer Affairs (OCAs) in nearly 40 State Mental Health Authorities was a significant development in the consumer movement. OCAs, which are generally staffed by consumers, introduce consumer perspectives into policy making and practices, encouraging consumer and family involvement and empowerment in government. By 1995, CMHS hired its first Consumer Affairs Specialist. Another key development was the passage of the Americans with Disabilities Act (ADA) in 1990, providing consumers with greater opportunities to obtain and maintain employment in fields outside the mental health sphere. In addition, the ADA makes provisions for training consumers to use the legislation appropriately, in turn increasing employers' awareness of the rights of their employees with disabilities and the responsibilities of employers in accommodating special needs in the work place (Furlong-Norman, 1991).

The Evidence Base of Consumer Run Services

Van Tosh and del Vecchio (2000) point out – and the draft COSP manual agrees – that research on and evaluation of consumer/survivor-operated programs has been limited and largely comprised of uncontrolled studies, demonstrations of feasibility, and preliminary findings. The draft COSP manual notes that research undertaken during the early development of consumer-operated programs tended to be limited to less rigorous expert reports and descriptive studies. These studies provided some evidence of the benefits of consumer-operated services, including improved quality of life (Chamberlin, Rogers and Ellison, 1996); improvements in problem solving, satisfaction, social support, and hospitalization reduction (Mowbray & Tan, 1993); and improved coping skills (Silverman, Blank & Taylor, 1997; Lewis, 2001), among others. Similarly, Van Tosh and del Vecchio reported on evaluation studies completed by individual programs that showed consumers/survivors are successful in providing services to their peers (Van Tosh, 1990). They also noted results from an NIMH Community Support Program-funded demonstration project that showed consumers/survivors are as effective as non-consumers /

survivors in providing case management services, as cited from Solomon (1992). Despite limited methodological rigor, these findings were considered promising.

Van Tosh and del Vecchio also note more recent improvements in research and evaluation, including two federally funded research centers and a cadre of independent researchers that are evaluating the impact of the mental health consumer/survivor self-help movement on both individual members and the larger mental health system. Consistent with Van Tosh and del Vecchio's observations, the draft COSP manual noted that since the Surgeon General's Report on Mental Health in 1999, the mental health field had seen a growth in the research base of controlled studies that demonstrate the effectiveness of peer practices in consumer-operated programs.

At the time of the publication of their technical report in 2000, Van Tosh and del Vecchio reported on preliminary research that suggested that the benefits of participation in consumer/survivor self-help included: "increased independence and self-reliance; improved self-esteem; enhanced coping skills and feelings of personal empowerment; and increased knowledge of services/rights, housing, employment, and other issues of special concern to mental health consumers/survivors" (pg. 13). Similar outcomes are summarized in the draft COSP manual involving a National Research Demonstration Grant funded by CMHS that investigated specialized self-help services in psychiatric crisis services through the Crisis Hostel, one of the first RCTs of a consumer-operated services program. Dumont and Jones (2002) found that in nearly all areas, persons assigned to the experimental group were associated with both better outcomes and lower costs when compared with a control group. They experienced greater levels of healing, empowerment and satisfaction; experienced less disruption in their work life; and had relatively less frequent and shorter hospital stays. In addition, crisis service costs and total mental health service costs were lower for the experimental group than for the control group.

A recent significant study described in the draft COSP manual is the COSP Multisite Research Initiative (1998-2006), which was initiated by CMHS and led by Campbell et al. (2006). This is the largest and most rigorous study of consumer-operated services programs conducted to date, with 1,827 participants at eight sites nationwide (four drop-in centers, two mutual support programs, two education/advocacy programs, and their respective control programs in the traditional mental health service system). Findings from this initiative support the conclusion that participation in consumer-operated services programs leads to significant additional increases in subjective aspects of both well-being and empowerment over increases achieved through traditional mental health services alone.

The primary focus of Van Tosh and del Vecchio's report (2000) is their examination of the findings from the National Institute of Mental Health's Community Support Program Consumer/Survivor-Operated Services Demonstration Projects (CSP Demonstration Projects), which took place in thirteen states: California, Colorado, Indiana, Maine, Missouri, New Hampshire, New York, Oregon, Tennessee, Vermont, Washington, West Virginia, and Wisconsin. While the authors clearly note the methodological limitations of this demonstration, they believe this "natural laboratory" provided useful "impressions and indications across these sites" (pg. 73).

In addition to exploring specific program elements, the authors provided an overview of evaluation findings. Overall, Van Tosh and del Vecchio reported that the hypothesis that consumers/survivors can successfully develop and operate autonomous service organizations was validated. They also noted that one of the "greatest measures of success was that over 70% of the initiatives were continued with the assistance of other funding sources," demonstrating that "these projects were successful in capturing ongoing financial support" (pg. 79).

Van Tosh and del Vecchio noted that all of the CSP Demonstration Projects reported that, as a result of these initiatives, consumers/survivors had achieved greater levels of independence, empowerment, and self-esteem, which helped improve a sense of confidence and self-efficacy. In addition, all of the projects reported that consumer/survivor quality of life was increased in various ways, including better income, housing, and friendships, as well as increased knowledge of rights and services. The authors note that these efforts helped people stay out of hospital settings and contribute positively to their communities.

"The development of social supports was a key success reported by over 60% of the projects," note Van Tosh and del Vecchio. They indicated that people felt more accepted and had greater numbers of friends, which in turn combated the social ostracism and loneliness that often accompanies mental health problems. In addition, the authors reported that all of the projects recorded an increase in employment skills and experience among consumers/ survivors participating in these efforts. Also, more than half of the projects reported success in increasing the knowledge of consumers/survivors in various areas such as rights, available services, communication, negotiations, working as a team, and organizational operations. These efforts also played an important role in educating the community about the positive abilities of consumers/survivors and to counter the often negative, stigmatizing portrayals.

The draft COSP manual cites several studies that support Van Tosh and del Vecchio's findings. For example, it elaborates on the Chamberlin, Rogers and Ellison (1996) report (also cited by Van Tosh and del Vecchio), a descriptive study demonstrating how members from six drop-in centers from across the nation experienced their involvement in self-help as leading to a positive effect on the quality of their lives, including general life satisfaction, feeling more positive about themselves, and feeling more productive. Similarly, the draft COSP manual cites Nelson et al. (2007), who reported that outcomes from their longitudinal study of Consumer/Survivor Initiatives (CSIs) in Ontario, Canada indicated that, at a 36 month follow-up, participants in CSIs scored significantly higher than non-active participants on measures of community integration, quality of life, and involvement in employment and/or education. Participants active in CSIs also scored significantly lower than non-active participants on measures of symptom distress.

Other studies cited in the draft COSP manual include Yanos et al. (2001), who showed that people involved in consumer-operated services programs had better social functioning than those involved only in traditional mental health services. Gordon et al. (1979) followed 80 consumers being discharged from a residential treatment facility's intensive skill building program (Early Intervention Program), comparing a group assigned to a community-based peer support system – Community Network Development (CND) – to a control group. At a ten

month follow-up, half as many CND participants required re-hospitalization as did controls, average total days of hospitalization was lower for CND participants than controls, and a significantly greater percentage of CND participants were able to function without contact with the mental health system. Anecdotal reports indicated that the most direct measure of the CND project effectiveness was increased social and instrumental supports available to participants.

Moving forward, Van Tosh and del Vecchio recommend more rigorous research of consumer/survivor-operated services, specifically endorsing that consumers/survivors be meaningfully involved in every stage of the process, from "conceptualization to data analysis to publication" (pg. 82). In addition they recommend examination of specific outcomes and other measures such as cost/benefit analyses; independence (including eliminating people's needs for Social Security and welfare benefits); the impact of self-help on specific subpopulations (including racial and ethnic minorities and women); recipient satisfaction with services; empowerment; and examining whether these programs serve those whose needs would not otherwise be met. In addition, the draft COSP manual recommends that further epidemiological study (across program and population types) will provide a broader base of information and could help elicit new and different outcomes. It also reinforced the need to identify skills, attitudes, knowledge and other core competencies in order to maintain high quality services, and suggested that new fidelity measures could be developed to accommodate a growing knowledge base.

Key Literature

denotes a study also summarized in the annotated bibliography from: Sommers, D., Campbell, J., and Rittenhouse, T. (1999)

Acker, C. (1990, July 16). Conference gives hope to patients. Philadelphia Inquirer, 1B.

Alcoholics Anonymous. (1994). The big book, 3rd edition. New York, NY: Alcoholics Anonymous World Services, Inc.

Campbell, J. (1998). Consumerism, outcomes, and satisfaction: A review of the literature. In R. Manderscheid & M. Henderson (Eds.), Mental health, United States, 1998 (pp. 11-28). Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Administration Center for Mental Health Services.

Campbell, J. (1998) The technical assistance needs of consumer/survivor and family stakeholder groups within state mental health agencies. Prepared for: National Technical Assistance Center for State Mental Health Planning. St, Louis, MO: Missouri Institute of Mental Health.

Campbell, J. (2005). Historical and philosophical development of peer run programs. In S. Clay (Ed.), On our own together: Peer programs for people with mental illness (pp. 17-64). Nashville, TN: Vanderbilt University Press.

Campbell, J., Dumont, J., & Einsphar, K. (1999). Peer Core Competencies Project. Philadelphia: Center for Mental Health Policy and Services Research.

Campbell, J., & Leaver, J. (2003). Emerging new practices in organized peer support. Report to the National Technical Assistance Center for State Mental Health Planning (NTAC). Alexandria, VA: National Association of State Mental Health Program Directors.

Campbell, J., Lichtenstein, C., Teague, G., Johnsen, M., Yates, B., Sonnefeld, J., et al. (2006). The Consumer-operated Service Programs (COSP) Multisite Research Initiative: Final Report. Saint Louis, MO: Coordinating Center at the Missouri Institute of Mental Health.

Campbell, J., Teague, G., Lichtenstein, C., Rogers, E. S., Banks, S., Chen, R., et al. (2007). Summary report of COSPMRI well-being and empowerment findings. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration: Rockville, MD.

Campbell, J. (1992). The Well-Being Project: Mental health clients speak for themselves. In Third annual conference proceedings on state mental health agency research. Alexandria, VA: National Association for State Mental Health Program Directors Research Institute.

Campbell, J. (1996). Towards collaborative mental health outcomes systems. New Directions for Mental Health Services, 71, 69-78.

Campbell, J. (1997a). The data needs of community based peer support programs. St. Louis, MO: Missouri Institute of Mental Health.

Campbell, J. (1997b). How consumers/survivors are evaluating the quality of psychiatric care. Evaluation Review, 21(3), 357-363.

Campbell, J., & Johnson, J. R. (1995). Struggling to reach common ground. Behavioral Healthcare Tomorrow, 4(3), 40, 45-46.

Campbell, J., Ralph, R., & Glover, R. (1993). From lab rat to researcher: The history, models, and policy implications of consumer/survivor involvement in research. Proceedings: Fourth annual national conference on state mental health agency services research and program evaluation, NASMHPD, Alexandria, VA, 138-157.

Campbell, J. & Schraiber, R. (1989). In pursuit of wellness: The Well-Being Project. Sacramento, CA: California Department of Mental Health.

Center for Mental Health Services. (2005). Building a foundation for recovery: How States can establish Medicaid-funded peer support services and a trained peer workforce. DHHS Pub. No. (SMA) 05-8088. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Center for Mental Health Services (November, 2007). Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft – The Evidence. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Chamberlin, J. (1978). On our own: Patient-controlled alternatives to the mental health system. New York: McGraw-Hill Co.

*Chamberlin, J. (1988). On our own: Patient-controlled alternatives to the mental health system. England: MIND.

Chamberlin, J. (1990). The ex-patient's movement: Where we've been and where we're going. Journal of Mind and Behavior 11, 323-36.

*Chamberlin, J. (1997). A working definition of empowerment. Psychiatric Rehabilitation Journal, 20, 43-46.

*Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric survivor movement. International Journal of Mental Health, 24, 39-46.

Chamberlin, J. (1997). A working definition of empowerment. Psychiatric Rehabilitation Journal, 20, 43-46.

Chamberlin, J. & Rogers, J. (1990). Planning a community-based mental health system. American Psychologist 45 (11), 1241-1244.

*Chamberlin, J., Rogers, E. S., and Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. Psychiatric Rehabilitation Journal, 19, 33-42.

Chamberlin, J., Rogers, J., and Sneed, C. (1989, June). Consumers, families, and community support systems. Psycho-Social Rehabilitation Journal 12(3), 93–106.

Copeland, M. E., & Mead, S. (2004). Wellness Recovery Action Plan and peer support: Personal, group, and program development. West Dummerston, VT: Peach Press.

Copeland, M. E. (1997). Wellness Recovery Action Plan. West Dummerston, VT: Peach Press.

*Corrigan, P. W. and Garman, A. N. (1997). Considerations for research on consumer empowerment and psychosocial interventions. Psychiatric Services, 48, 347-352.

Culwell, D.H. (1992). The national mental health consumer scene. The Journal of the California Alliance for the Mentally Ill 3 (2), 40-42.

Deegan, P. E. (2001). The Politics of Memory. Sea Rose Productions.

Deegan, P.E. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal 11 (4), 11-19.

Deegan, P. E. (1992). The independent living movement and people with psychiatric disabilities: Taking back control over our own lives. Psychosocial Rehabilitation Journal, 15, 3-19.

Deegan, P. (1993, April). Recovering Our Sense of Value After Being Labeled Mentally Ill. Journal of Psychosocial Nursing.

*Dixon, L., Krauss, N., and Lehman, A. (1994). Consumers as service providers: The promise and challenge. Community Mental Health Journal, 30, 615-625.

Dumont, J., & Jones, K. (2002, Spring). Findings from a consumer/survivor defined alternative to psychiatric hospitalization. Outlook, 4-6.

Emerick, R. (1990). Self-help groups for former patients: Relations with mental health professionals. Hospital and Community Psychiatry 41 (4a), 401-407.

Essock, S., Goldman, H., Van Tosh, L., Anthony W., Appell C., Bond, G., et al. (2003). Evidence-based practices: Setting the context and responding to concerns. Psychiatric Clinics of North America, 26(4), 919-938.

Fleischer, D. Z., & Zames, F. (2001). The disability rights movement: From charity to confrontation. Philadelphia: Temple University Press.

Frese, F.J. & Davis, W.W. (1997). The consumer-survivor movement, recovery, and consumer professionals. Professional Psychiatry, Research and Practice 28 (3), 243-245.

Fricks, L. (2005). Building a foundation for recovery: How states can establish Medicaid-funded peer support services and a trained peer workforce. DHHS Pub. No. (SMA) 05-8088. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Furlong-Norman, K. (Ed.). (1988, November). Community Support Network News, 5(2).

Goldstrom, I. D., Campbell, J., Rogers, J. A., Lambert, D. B., Blacklow, B., & Henderson, M. J. (2005). Mental health consumer organizations: A national picture. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Goldstrom, I. D., Campbell, J., Rogers, J. A., Lambert, D. B., Blacklow, B., Henderson, M. J., & Manderscheid, R. W. (2006). National estimates for mental health mutual support groups, self-help organizations, and consumer-operated services. Administration and Policy in Mental Health, 33(1), 92-103.

Gordon, R., Edmunson, E., Bedell, J., & Goldstein, N. (1979). Utilizing peer management and support to reduce rehospitalization of mental patients. Journal of the Florida Medical Association, 66(9), 927- 933.

Hardiman, E. R. (2004). Networks of caring, a qualitative study of social support in consumer-run mental health agencies. Qualitative Social Work, 3, 431-448.

Hardiman, E. R. (2005). Evidence based practice in mental health: Implications and challenges for consumer-run programs. Best Practices in Mental Health, 1(2), 105-122.

Hardiman, E. R., & Segal, S. P. (2003). Community membership and social networks in mental health self-help agencies. Psychiatric Rehabilitation Journal, 27(1), 25-33.

Interagency Council on the Homeless. (1991). Reaching out: A guide for service providers. National Institute of Mental Health. Rockville, MD: The National Resource Center on Homelessness and Mental Health.

Interagency Council on the Homeless. (1992, February). Outcasts on Main Street: Report of the Federal Task Force on Homelessness and Severe Mental Illness. National Institute of Mental Health.

Johnsen, M., Teague, G., & McDonel-Herr, E. (2005). Common ingredients as a measure for peer run programs. In S. Clay (Ed.), On our own together: Peer programs for people with mental illness (pp. 213-238). Nashville, TN: Vanderbilt University Press.

Kaufmann, C. (1995). The self-help employment center: Some outcomes from the first year. Psychosocial Rehabilitation Journal, 18, 145- 162.

Kaufmann, C. & Freund, P. (1988). Self-help and peer mutual support in community mental health: A model for peer-professional collaboration. Pittsburgh, PA: Author.

Kaufmann, C., Schulberg, H., & Schooler, N. (1994). Self help group participation among people with severe mental illness. Prevention in Human Services, 11, 315-331.

*Kaufmann, C. L., Ward-Colasante, C., and Farmer, J. (1993). Development and evaluation of drop-in centers operated by mental health consumers. Hospital and Community Psychiatry, 44, (7), 675-678.

Kropotkin, P. (1972). Mutual aid: A factor of evolution. New York: New York University Press. (Original work published 1902).

Leete, E. (1988, June). The role of the consumer movement and persons with a mental illness. Switzer Seminar #12.

Leete, E. (1988). A consumer perspective on psychosocial treatment. Psychosocial Rehabilitation Journal, 12, 45-52.

Leff, S., Campbell, J., Gagne, C., & Woocher, L. (1997). Evaluating peer providers. In C. Mowbray, D. Moxley, C. Jasper & L. Howell (Eds.), Consumers as providers in psychiatric rehabilitation (pp. 488-501). Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Lewis, L. (2001). Role of mental health patient organizations in disease management. Practical Disease Management, 9(11), 604-617.

Lieberman, A., Gowdy, E., & Knutson, L. (1991). The mental health outreach project: A case study in self-help. Psychosocial Rehabilitation Journal, 14(3), 100-105.

*Lieberman, M. A. and Snowden, L. R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings, (32-49). Thousand Oaks, CA: SAGE Publications.

MacNeil, C., & Mead, S. (2005). A narrative approach to developing standards for trauma-informed peer support. American Journal of Evaluation, 26, 231-244.

Madness Network News Reader. (1974). San Francisco, CA: Glide Publications.

Magura, S., Laudet, A., Mahmood, D., Rosenblum, A., & Knight, E. (2002). Adherence to medication regimens and participation in dual-focus self-help groups. Psychiatric Services, 53, 310- 316.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. Psychiatric Rehabilitation Journal, 25, 134-141.

Mowbray, C. T., Holter, M. C., Stark, L., Pfeffer, C., & Bybee, D. (2005). A Fidelity Rating Instrument for Consumer-Run Drop-in centers (FRI-CRDI). Research on Social Work Practice, 15, 278-290.

Mowbray, C., & Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. Innovations and Research, 1(2), 19-23.

Mowbray, C., & Tan, C. (1993). Consumer-operated drop-in centers: Evaluation of operations and impact. Journal of Mental Health Administration, 20(1), 8- 19.

Mowbray, C., Moxley, D., Jasper, C., & Howel, L. (Eds.) Consumers as providers in psychiatric rehabilitation. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Mowbray, C., Wellwood, R., & Chamberlain, P. (1988). Project Stay: A consumer-run support service. Psychosocial Rehabilitation Journal, 12, 33-42.

*Mowbray, C. T., Chamberlain, P., Jennings, M., and Reed, C. (1988). Consumer-run mental health services: Results from five demonstration projects. Community Mental Health Journal, 24, 151-156.

*Mowbray, C. T. and Moxley, D. P. (1997). A framework for organizing consumer roles as providers of psychiatric rehabilitation. In Mowbray, C. T., Moxley, D., Jasper, C. A., and

Howell, L. L. (eds), Consumers as providers in psychiatric rehabilitation, 35-44. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

*Mowbray, C. T., Moxley, D. P., Thrasher, S, Bybee, D., McCrohan, N., Harris, S., and Clover, G. (1996). Consumers as community support providers: Issues created by role innovation. Community Mental Health Journal, 32, 47-66.

*Mowbray, C. T. and Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. Innovations and Research, 1, 19-23.

Moxley, D., & Mowbray, C. (1997). Consumers as providers: Forces and factors legitimizing role innovation in psychiatric rehabilitation. In C. Mowbray, D. Moxley, C. Jasper, & L. Howel (Eds.), Consumers as providers in psychiatric rehabilitation (pp. 2-33). Columbia, MD: International Association of Psychosocial Rehabilitation Services.

Nelson , G., Ochocka, J., Janzen, R., Trainor, J., Goering, P., & Lomotey, J. (2007). A longitudinal study of mental health consumer/survivor initiatives: Part V – Outcomes at three-year follow-up. Journal of Community Psychology, 35, 655- 665.

New Freedom Commission on Mental Health. (2003). Achieving the promise: Transforming mental health are in America. DHHS Pub. No. SMA-03-3831: Rockville, MD: Substance Abuse and Mental Health Services Administration.

President's Commission on Mental Health. (1978). Report to the President 1. Washington, DC: U.S. Government Printing Office.

Ralph, R. (2000). Recovery. Psychiatric Rehabilitation Skills, 4, 480-517.

*Rappaport, J. (1994). Narrative studies, personal stories, and identity transformation in the mutual-help context. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings (115-135), Thousand Oaks, CA: SAGE Publications.

Rappaport. J. (1985) The power of empowerment language. Social Policy, 16 (2) 15-22.

Roberts, L. & Rappaport, J. (1989). Empowerment in the mutual help context: An empirical analysis of the value of helping others. Lansing, MI: Author.

Sabin, J. E., & Daniels, N. (2001). Strengthening the consumer voice in managed care: I. Can the private sector meet the public sector standard? Psychiatric Services, 52, 461-462, 464.

Sabin J. E., & Daniels, N. (2002). Strengthening the consumer voice in managed care: III. The Philadelphia Consumer Satisfaction Team. Psychiatric Services, 53, 23-24, 29.

Sabin J. E., & Daniels, N. (2002). Strengthening the consumer voice in managed care: IV. The Leadership Academy Program. Psychiatric Services, 53, 405- 406,411.

Sabin J. E., & Daniels, N. (2002). Strengthening the consumer voice in managed care: V. Helping professionals listen. Psychiatric Services, 53, 805-811.

Sabin J. E., & Daniels, N. (2003). Strengthening the consumer voice in managed care: VII. The Georgia peer specialist program. Psychiatric Services, 54, 497-98.

Sabin, J. E., O'Brien, M. F., & Daniels, N. (2001). Strengthening the consumer voice in managed care: II. Moving NCQA standards from rights to empowerment. Psychiatric Services, 52, 1303-1305.

Salzer, M., & Liptzin-Shear, S. (2002). Identifying consumer provider benefits in evaluation of consumer-delivered services. Psychiatric Rehabilitation Journal, 25, 281.

Salzer, M., & Mental Health Association of Southeastern Pennsylvania Best Practices Team (2002). Consumer-delivered services as a best practice in mental health care delivery and the development of practice guidelines. Psychiatric Rehabilitation Skills, 6, 355-382.

Schlageter, C. (Ed.). (1990, March). OMH News II(1). New York State Office of Mental Health.

Segal, S., Silverman, C., & Temkin, T. (1995a). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31(3), 215-227.

*Segal, S. P., Silverman, C., and Temkin, T. (1995). Characteristics and service use of long-term members of self-help agencies for mental health clients. Psychiatric Services, 46, 269-274.

*Segal, S. P., Silverman, C., and Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31, 215-227.

Segal, S. P., Silverman, C., & Temkin, T. (1993). Empowerment and self-help agency practice for people with mental disabilities. Social Work, 38(6), 705-712.

Silverman, S., Blank, M., & Taylor, L. (1997). On our own: Preliminary findings from a consumer run service model. Psychiatric Rehabilitation Journal, 21(2), 151-159.

*Solomon, P. (1994). Response to "Consumers as service providers: The promise and challenge." Community Mental Health Journal, 30, 631-634.

Solomon, P. (1992, July-September). Consumer case management evaluation: CSP/NIMH grant. OutLook 2(2), 11–12. Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.

*Solomon, P. and Draine, J. (1994). Family perceptions of consumers as case managers. Community Mental Health Journal, 30, 165-176.

*Solomon, P. and Draine, J. (1994). Satisfaction with mental health treatment in a randomized trial of consumer case management. The Journal of Nervous and Mental Disease, 182, 179-183.

*Solomon, P. and Draine, J. (1996). Perspectives concerning consumers as case managers. Community Mental Health Journal, 32, 41-46.

Solomon, P. (2004). Peer support/peer provided services: Underlying process, benefits and critical ingredients. Psychiatric Rehabilitation Journal, 27, 392–401.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. Psychiatric Rehabilitation Journal, 25, 20-27.

Sommers, D., Campbell, J., and Rittenhouse, T. (1999). Annotated bibliography on consumer—operated sevices. Missouri Institute of Mental Health Program in Consumer Studies and Training, St. Louis, MO: Supported through a subcontract with the Center for Mental Health Policy and Services Research, University of Pennsylvania: Philadelphia.*

Specht, D. (Ed.). (1988, June). Highlights of the findings of a national survey on state support of consumer/ex-patient activities. Holyoke, MA: Human Resource Association of the Northeast.

Specht, D. (ed.). (1998). Highlights of the findings of a national survey on state support of consumer/ex-patients activities. Holyoke, MA: Human Resource Association of the Northeast.

Twedt, S. (1990, July 15). Mental patients rally in search of a fair chance and fewer labels. Pittsburgh Press. A6.

U.S. Department of Education. (1990, Winter). Training students with learning disabilities for careers in the human services. OSERS News in Print! III(3). Office of Special Education and Rehabilitative Services.

U. S. Department of Health and Human Services, Office of the Surgeon General. (1999). Mental health: A report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (1998). Guidance for applicants No. SM 98-004: Cooperative Agreements to Evaluate Consumer-Operated Human Service Programs for Persons with Serious Mental Illness. Rockville, MD: Author.

U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2005). Free to choose: Transforming behavioral health care to self-direction. DHHS Publication No. SMA-05-3982. Rockville, MD: Author.

Van Tosh, L., & del Vecchio, P. (2001). Consumer-operated self-help programs: A technical report. Rockville, MD: Center for Mental Health Services.

Van Tosh, L., Ralph, R., & Campbell, J. (2000). The rise of consumerism. Psychiatric Rehabilitation Skills, 4, 383-409.

Van Tosh, L. (1988, July). The benefits of consumer-run homeless programs to the mental health system. Notes from CHAMP, 8–9.

Van Tosh, L. (1989a, March). Consumer choice for the homeless mentally ill. Reaching out: Focus on the homeless mentally ill 1(2).

Van Tosh, L. (1989b, December). Helping people help themselves—Project OATS is a pioneer in consumer-run services. ACCESS 1(4), 1–2.

Van Tosh, L. (1990, October). Final report and evaluation of Project OATS. Philadelphia, PA: Mental Health Association of Southeastern Pennsylvania.

Van Tosh, Laura & del Vecchio, Paolo. (In press). Consumer/Survivor-operated self-help programs: A technical report. Washington, DC: U.S. Department of Health and Human Services.

*Van Tosh, L. (with Finkle, M., Hartman, B., Lewis, C., Plumlee, L., and Susko, M. A.). (1993). Working for a change: Employment of consumers/survivors in the design and provision of services for persons who are homeless and mentally disabled. Center for Mental Health Services, 1-27.

Yanos, P., Primavera, L., & Knight, E. (2001). Consumer-run service participation, recovery of social functioning, and the mediating role of psychological factors. Psychiatric Services, 52, 493-500.

Appendix Three: The History and Evidence Base of Peer to Peer Support by Parents and Caregivers of Children and Youth

History and Development of Family Peer to Peer Support

The system of care approach has fundamentally changed the relationships of families of children and youth involved in child-serving systems have with the agencies involved. Increasingly, collaboration and partnership between families and service providers have been recognized as the threads that link successful programs, policies, and practices. Over the past ten years many federal and state policies have begun to mandate parent and caregiver involvement. Many states now allow funding, through both Medicaid and state dollars, to support family members in provider and staff roles. In 2006, 21 states reported that they permit Medicaid reimbursement for families working in various practice-related roles (Cooper, 2008). Parents and caregivers provide services, act as advocates for change, mentor other families, shape programs, create policies, and carry out public service agendas. The principle of parents and professionals working collaboratively as partners is now widely recognized as a best practice.

In order to be respectfully inclusive of the many types of family and kin relationships that may provide peer support, the term *family peer to peer support* is used in this section. The term was recently developed by the Federation of Families for Children's Mental Health (Slaton, 2008). However, literature and discussion of the model uses terms including parent partners, parent to parent and family to family support.

The development of family peer to peer support is closely linked to both the broader family empowerment movement (Huff, 1998; Slaton, 2008) and the growth of consumer provided services (Solomon & Draine, 2001). It is also informed by the large body of research and the corresponding acceptance of the centrality of peer social support in the healing and recovery process. Peer to peer support may be understood as a mechanism for peer social support. Social support as defined by Brown (1996) encompasses "social relationships... information, nurturance, empathy, encouragement, validating behaviour, constructive genuineness, sharedness and reciprocity, instrumental help, or recognition of competence." Increasing social support is a time-honored, well-respected method of enhancing treatment, and peer support has been a cornerstone of the developmental disability field since 1975 when parent-to-parent support groups were instituted. This model of peer support and advocacy is used with great success in many other health and human service disciplines (Hoagwood, Green, Kelleher, Schoenwald, et al., 2008).

Consumer provided services are defined by Solomon & Draine (2001) as "services provided by consumers… who are employed to deliver services to others" (p. 21). Family peer to peer support may be defined as a consumer delivered service in which the parents (or other kin) providing support have direct experiential knowledge (shared experiences) with the parent receiving support. It is generally accepted that it is necessary that the parents or kin providing support have shared similar experiences with those receiving support and were previously or are currently consumers of similar services (Slaton, 2008; Hoagwood, Green, Kelleher, Schoenwald, et al., 2008). This peer support builds connections that provide positive role

models, reduce the sense of isolation and support parents as they journey through service systems.

The beginning of the family peer to peer support movement can be traced back twenty to thirty years as parents of high-needs children who had successfully navigated the challenges of the mental health system wanted to support other families going through the same thing. This peer to peer support became a valuable resource for service providers as well as for the families being served. In the middle 1980s the movement began to take formal shape with the first Families as Allies conference sponsored by Portland State University Research and Training Center on Family Support in 1986. The conference sought to promote families and professionals working together and to afford families an opportunity to network across states. With federal funding for the Child and Adolescent Service Systems Program (CASSP), families were increasingly included in national meetings and asked to share their experiences. In 1989 the Federation of Families for Children's Mental Health (the Federation) was incorporated, opening a national office in 1992. Since then the Federation has served as an organizing voice for family empowerment and has fostered the growth and acceptance of family peer to peer support through training and advocacy (Huff, 1998; Slaton 2008).

As the value of family peer to peer support has been increasingly accepted, the Center for Medicaid Services (CMS) provided guidance on how peer support may be Medicaid reimbursable. Many states now allow funding through Medicaid and state sources to support family members and youth in provider or staff roles. In a 2006 survey, 21 states reported that they permit Medicaid reimbursement for families working in various practice related roles. For youth 14 states permit Medicaid reimbursement to youth in service related roles (Cooper, 2008).

The Evidence Base for Family Peer to Peer Support

Family peer to peer support is now found in most communities throughout the country. There is, however, a wide range in the types of programs and the settings in which they are found (Hoagwood et al., 2007; Santelli et al., 1997). Programs operating under the umbrella of the peer to peer support model range from simply offering resources and information to parents, to providing peer to peer emotional, informational and even therapeutic support. In the children's mental health field, a recent national survey of family organizations found that education, advocacy, and peer-to-peer support are primary roles for families (Hoagwood et al., 2007).

Ireys, DeVet and Sakwa (1998), in reviewing family peer to peer support models, provided a useful conceptualization of the key mechanisms underlying the effectiveness of this approach. They identified four key areas:

- **Social support** helps caregivers to feel a sense of being valued and belonging, as well as to receive new resources, both tangible and intangible.
- Peer supporters as **links to broader social networks**, in which peer support functions as a link to community resources, people, or institutions and thus serves as a relationship or social network bridge-builder.
- **Social comparison** occurs when caregivers are more able to maintain and build self esteem in the context of receiving support from a peer who has been through a similar experience, as opposed to situations where unintended negative consequences emerge as supports or

services are received from someone who has not experienced similar challenges. Because of similar experiences, the peer can understand what the person is going through, but avoid the potential negative consequences of threatening comparisons.

- **Empowerment** appears to be supported through the peer to peer interaction as caregivers see the peer supporter as a model of success and as they learn strategies and access resources to help deal with their child's and family's situation.

The literature base for family peer to peer support is growing rapidly but consists mostly of articles focused on advocacy, anecdotal accounts and policy oriented briefs. While the research base for the effectiveness of family peer to peer support is emerging, empirical studies of the model are difficult to uncover and studies vary in purpose and design. A recent literature review sponsored by the University of South Florida (USF) Research and Training Center for Children's Mental Health (Robbins, et al., 2008) provides an excellent survey and synthesis of available literature and served as a primary source for this appendix.

Corresponding to the growth of the family movement in the middle 1980s and 1990s, almost all available literature was published over the past ten to fifteen years. The USF Research and Training Center literature review found over 5000 articles pertaining to family peer to peer support. This large body of work included only 31 actual studies pertaining to peer to peer support. These studies were of five designs: (a) topical discussion (n=4; 13%); (b) descriptive (n=11; 35%); (c) qualitative (n=4, 13%); (d) quasi-experimental (n=3; 10%); and (e) random control design (n=9; 29%). Within each category, the articles were further divided into three categories based on their topic: (a) mental health (n=11; 35%), which refers to studies in which participants were parents of children in need of mental health services; (b) disability or chronic illness (n=18; 58%), which refers to studies in which participants were parents of children with physical disabilities, premature birth, and/or chronic illnesses; and (c) general parenting (n=2; 7%), which refers to articles that did not have a disability-specific purpose for parent support (Robbins, et al., 2008).

Reflecting the emerging nature of the family peer to peer support movement, the first step in exploring the evidence base is to review the various definitions of peer to peer support across the studies. In the available literature, definitions ranged from generic (veteran parents sharing their experiences) to comprehensive and manualized models with training and supervision. A general consensus existed across studies, though, that family peer to peer support addresses the needs of parents or other kin coping with children with a variety of problems (e.g., mental health and chronic illness) by other parents or family members who have shared a similar experience and can offer direct and/or indirect support in various forms.

In order to offer the reader a sense of the range of conceptualization of the family peer to peer construct, the following table, based on the Research and Training Center's review (Robbins, et al., 2008), presents the definitions of peer to peer support used across the available research base.

Family Peer to Peer Support – Definitions Across 26 Studies		
Topic	**Study**	**Definition**
Mental Health	Ireys, DeVet, & Sakwa (1998)	Social support is defined as information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations.
	Adams, Westmoreland, Edwards, & Adams (2006)	Connections with parents who have had similar experiences.
	Koroloff & Friesen (1991)	Support includes a combination of functions (information, parent-to-parent support, advocacy), and may be formally constituted, affiliated with larger formal organizations, or simply informal meetings with fewer participants.
	Santelli, Turnbull, Marquis, & Lerner (1995)	"Parent to parent programs provide emotional and informational support to parents of children with special needs by matching a trained veteran parent in a one-to-one relationship with a parent newly referred to the program."
	Santelli, Turnbull, Marquis, & Lerner (1993)	Parent-to-parent programs provide emotional and informational support through one-to-one matches. This support is more informal, flexible, spontaneous, and individualized than the support that is generated in group settings.
	Vandereycken & Louwies (2005)	Parents provided support to parents with whom they've shared a similar experience (specifically, raising a child with an eating disorder).
	Slowik, Willson, & Loh, (2004)	Parent support groups offer the opportunity for problem sharing and containment of anxiety through a psychosocial network.
	Ireys & Sakwa (2006)	"Information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations."
	Rhodes, Bailee, Brown, & Madden (2008)	"Parent-to-parent consultations offered families an intense emotional experience which empowered them with the hope to believe that they too could achieve the goal of recovery."
Disability/Illness	Hartman, Radin & McConnell (1992)	"Peer support provides benefits of experiential learning and helps to connect families with each other. "
	Santelli, Turnbull, Marquis, & Lerner (1997)	Programs help parents who have children with special needs find each other and become reliable allies for each other. They provide parents with the opportunity to connect with and support each other through informational and emotional support, and through reciprocity.
	Baum (2004)	Parent-to-parent support mediated by computers.
	Foreman, Willis, & Goodenough (2005)	To provide parents with an opportunity to access information relevant to their child's treatment and living with a life-threatening illness, as well as to meet other parents in similar situations.

Family Peer to Peer Support – Definitions Across 26 Studies		
Topic	**Study**	**Definition**
	Ireys, Chernoff, Stein, DeVet, & Silver (2001)	"Information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations." Includes further descriptions of informational, emotional, and affirmational supports.
	Santelli, Turnbull, Marquis, & Lerner (2000)	"Parent-to-parent programs provide emotional and informational support to parents of children who have special needs. New parents are helped to interpret and understand the system and to find the best possible services for their young children with special needs."
	Santelli, Turnbull, Sergeant, Lerner, & Marquis (1996)	Programs match referred parents with a veteran parent who develops a one-to-one relationship in which the parents arrange their own supportive interactions, including informational and emotional supports.
	Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis, & Santelli. (1998)	Support from similar others.
	Konrad (2007)	"Veteran parents can provide parents of newly diagnosed children with personal and practical recommendations for managing and adapting to unexpected life circumstances."
	Ireys & DeVet (2001)	"Information leading people to believe that they are esteemed and valued and that they belong to a network of mutual obligations."
	Palit & Chatterjee (2006)	"Support services for parents of disabled students in which support is provided by a team of volunteer parents who themselves have children with disabilities. Support aims to reduce stress, insecurity, and helplessness, and to develop motivational level, patience, and tolerance."
	Roman, Lindsay, Boger, DeWys, Beaumont, Jones, & Haas (1995) (	Veteran parent support as adapted for the NICU was defined as emotional, informational, and appraisal support provided by an experienced, volunteer parent of a preterm infant to a parent of a preterm infant for the purpose of increasing parents' environmental resources.
	Ireys, Chernoff, DeVet, & Kim (2001)	"Information leading people to believe that they are esteemed and valued and that they belong to a network of mutual obligations."
	Ireys, Sills, Kolodner, & Walsh (1996)	The program focused on enhancing three types of social support, informational support (sharing information about services, practical tips for dealing with teachers and health providers), affirmational support (praising the mother's parenting, identifying their competencies and providing positive feedback), and emotional support (listening to mothers' concerns, demonstrating continued interest in experiences, and communicating an understanding of feelings and concerns).

Family Peer to Peer Support – Definitions Across 26 Studies		
Topic	Study	Definition
General Parenting	Preyde & Ardal (2003)	A connection with a parent who has shared experiential knowledge.
	Silver, Ireys, Bauman, & Stein (1997)	"To improve the mother's psychological status by increasing her social support and access to relevant information, services, and knowledgeable advisors… To make mothers feel more empowered and active participants in their children's health care… To discuss specific issues related to the child's health condition, and attempt to identify and address the needs and concerns of other family members as well."
	Hogan, Linden, & Najarian (2002)	An exchange between providers and recipients that provides emotional (verbal and nonverbal communication of caring and concern), informational (the provision of information used to guide or advise), and instrumental (the provision of material goods, such as money, transportation, and physical assistance) support.

Empirical Support for Family Peer to Peer Support

Of the thirty one studies identified by Robbins and her colleagues (2008), nine featured research designs with rigorous enough methods to support examination of the outcomes of family peer to peer support. Of these nine studies, only three focused on families with children experiencing mental health issues.

The targeted outcomes in these studies focused primarily on the effects of peer to peer support on the emotional functioning of parents (anxiety, depression, anger, or inadequate coping skills). All of the seven studies with this focus found positive results. That is, parents found peer to peer support enhanced their emotional functioning by alleviating feelings of anxiety, depression and anger and increasing their coping skills (e.g., Ireys, & Sakwa, 2006; Silver, et al., 1997). Two studies explored level of empowerment of family members, with one study finding positive results (Elliot et al., 1998) and the other finding no changes in empowerment levels. Finally, one study included an examination of service use and reported that family peer to peer support increases service initiation, but that these effects were not sustained over time (Elliot, at al., 1998).

> While only a few studies featured quantitative designs that supported outcome analysis, those that did demonstrated positive results for emotional functioning, empowerment or service use.

There were far more descriptive and qualitative studies available for review, and results for these studies were overwhelmingly positive. There is little doubt that parents find family peer to peer support helpful and valuable. A national survey of family mental health organizations confirms that over 90% of respondents reported that providing peer to peer support is one of the most important roles for families, and 85% of family mental health organizations surveyed reported providing peer to peer support for parents or other kin providing care to children with mental health disorders (Hoagwood, et al., 2008). Other studies demonstrated that caregivers

felt reduced isolation and an increased sense of being supported through peer to peer support (Ainbinder, et al., 1998) and that parents or other caregivers of children with special needs are uniquely qualified to help one another (Kerr & McIntosh, 2000).

> Results of qualitative and descriptive studies are clear – caregivers of children with mental health disorders find peer to peer support helpful and valuable.

In conclusion, the empirical base for family peer to peer support is limited but growing. The results from available literature are, however, encouraging. Family peer to peer support programs are valued by caregivers and may improve emotional functioning of parents who have children with disabilities and help them improve their coping skills. The wide variety of definitions for peer to peer support in the literature also points to the need for conceptual and theoretical refinement. Robbins and her colleagues (2008) note that this refinement represents a necessary step before the research base will be able to clearly explore how effective family peer to peer support works to produce improved emotional functioning for caregivers, increased access to services, better partnerships with providers, and ultimately improved outcomes for children.

References

Ainbinder, J. G., Blanchard, L. W., Singer, G. H. S., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. Journal of Pediatric Psychology, 23(2), 99-109.

Elliot, D. J., Koroloff, N. M., Koren, P. E., & Friesen, B. J. (1998). Improving access to children's mental health services: The Family Associate approach. In M.H. Epstein, K. Kutash, & A. Duchnowski (Eds.), Outcomes for Children and Youth with Emotional Disorders and their Families: Programs and Evaluation Best Practices (pp. 581-609). Austin, TX: Pro-Ed.

Ireys, H. T., & Sakwa, D. D. (2006). Building family-to-family support programs: Rationale, goals, and challenges. Focal Point 20(1), 10-14.

Ireys, H. T., DeVet, K. A., & Sakwa, D. (1998).Family support and education. In M.H. Epstein, K. Kutash, & A.J. Duchnowski (Eds.), Outcomes for Children and Youth with Emotional Disorders and their Families: Programs and Evaluation Best Practices (pp. 154-175). Austin, TX: Pro-Ed.

Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. Child: Care, Health, and Development, 26(4), 309-322.

Hoagwood, K. E., Green, E., Kelleher, K., Schoenwald, S., Rolls-Reutz, J., Landsverk, J., Glisson, C., & Mayberg, S. (2008). Family Advocacy, Support and Education in Children's Mental Health: Results of a National Survey. Admin Policy Mental Health, *35*, 73 - 83.

Huff, B., (1998). Federation celebrates 10 year anniversary. Claiming Children, Spring 1998.

Robbins, V., Johnston, J., Barnett, H., Hobstetter, W., Kutash, K., Duchnowski, A. J., & Annis, S. (2008). *Parent to parent: A synthesis of the emerging literature*. Tampa, FL: University of

South Florida, The Louis de la Parte Florida Mental Health Institute, Department of Child & Family Studies.

Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (1997). Parent-to-parent programs: A resource for parents and professionals. Journal of Early Intervention, 21(1), 73-83.

Slaton, E. (September 4, 2008). Personal communication.

Silver, E. J., Ireys, H. T., Bauman, L. J., & Stein, R. E. K. (1997). Psychological outcomes of a support intervention in mothers of children with ongoing health conditions: The parent-to-parent network. Journal of Community Psychology, 25(3), 249-264.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. Psychiatric Rehabilitation Journal, 25(1), 20 – 27.

Appendix Four – The History and Evidence Base for Youth Involvement in Mental Health Systems of Care

History and Development of Youth Involvement in Mental Health Systems of Care

The development of youth involvement in mental health systems of care closely follows the growth and acceptance of family peer to peer support and the broader family empowerment movement (Huff, 1998; Slaton, 2008), as well as the growth of consumer provided services (Solomon & Draine, 2001). Over the past 15 years, the family movement has led the way for positive change in children's mental health services. The youth movement is following a path similar to that of the family movement. Youth are viewed as valuable partners and experts on their own needs. Youth involvement in policymaking has steadily risen. Some of the organizations that have helped support this development are the Federation of Families for Children's Mental Health, the Children's Defense Fund, and the Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services (CMHS). Their willingness to have youth involvement at their annual conferences has helped youth to educate more young people, families, and professionals on the value of youth involvement, engagement, and empowerment. (Matarese, McGinnis, & Mora, 2005).

Milestones
Beyond the direct link to the broader family movement, there appear to be at least two important milestones in the emergence of youth as full partners in mental health systems of care. The first was the Surgeon General's Conference on Child Mental Health in September 2000. This was a pioneering conference where young people were invited to "sit at the table" with families and professionals to discuss the Surgeon General's focus on children's mental health. While the intent of the meeting organizers and adult participants was to include youth, youth did not feel able to participate in a meaningful way. That day, participating youth unanimously decided to not attend the conference on the second day due to what they identified as a lack of respect. Instead the youth worked together to develop a "manifesto" to make adults aware of their needs and to ask for respect and dignity in the way they were treated (Matarese, McGinnis & Mora, 2005). Among the requests were to:
- Not use acronyms without explanations that youth would understand,
- Not use acronyms, labels and diagnoses to describe youth in meetings (e.g., an "SED kid"),
- Fund and support youth organizations at the same level as family organizations, and
- Make room for youth to participate when they are asked to sit at policy tables.

The second milestone followed the next year at the System of Care Community Meeting in Puerto Rico. At this conference youth were invited to facilitate a discussion on the needs of youth in mental health systems of care across the nation. Building on the manifesto developed the previous year, participating youth developed a list of recommendations for their communities and national policymakers. These included:
- Involving youth in all policymaking and governing bodies,
- Providing access to resources and skills to make youth effective advocates,
- Promoting collaboration between youth and family organizations,

- Building a mutual relationship between consumers and professionals, with a goal of shared power,
- Hearing and utilizing youth voice,
- Developing a youth curriculum for professionals and youth coordinators,
- Developing a national, recipient-run youth organization,
- Coordinating an annual youth/young adult conference,
- Hiring of a youth coordinator at a national level who has been a recipient of services, and
- Requiring CMHS Request for Applicants to ensure:
    - Youth involvement,
    - Youth participation in all conferences, and
    - Hiring local youth coordinators.

These two events and corresponding recommendations marked a shift in the way youth are seen and participate in policy-making and delivery of services within child and family mental health systems of care. A clear indicator of the shift may be seen in the current Request for Applicants (RFA) for SAMHSA's flagship Child Mental Health Initiative (CMHI). The RFA requires youth involvement with the hiring of local youth coordinators and ensures youth involvement in every level of system of care development. To respond to this new requirement, the Technical Assistance Partnership for Child and Family Mental Health has hired a full-time national youth resource specialist dedicated to supporting the various youth groups and system of care communities across the nation.

Youth Engagement Beyond Mental Health Systems of Care

An internet search identified more than 40 youth led groups dedicated to youth voice in public policy across the country. The rise of youth involvement in mental health systems of care is taking place within the larger context of the positive youth development movement and the increasing engagement of youth in the broad policy and community development arena.

Youth engagement is a relatively new, but growing, approach to youth development. Youth engagement approaches in the field include: youth service, youth media, youth philanthropy, youth in research and evaluation, youth civic engagement, youth organizing, youth decision-making and governance, and youth leadership development (Gray & Hayes, 2008). The authors of a recent review place these approaches along a continuum from youth service, which includes individual activities, to youth civic engagement, which includes more engaging and purposeful collective actions. Youth engagement has been defined as the intentional, meaningful, and sustained involvement of young people in a decision-making activity (Gray & Hayes, 2008). It can be an integral feature of many different types of programs and services for youth, or it can be the core focus of a specific program. Youth engagement can be made available by large and small, public and private organizations in diverse settings, such as schools, workplaces, and community facilities. It aims to help young people develop the capacity and confidence to participate as productive partners in decisions affecting them individually and collectively.

The positive youth development movement is also useful in understanding the growing support for youth engagement as full partners in systems of care. Positive youth development marks a shift in the way the mental health community thinks about young people from an almost exclusive emphasis on prevention and treatment targeting problems of high-risk youth to an emphasis on preparation that develops skills and encourages successful development (Zeldin, 1995). One of the central tenets of positive youth development is the importance of creating opportunities for youth to be engaged in their communities. Literature in the positive youth development field suggests that youth participation in activities such as community teams may support healthy development (Hyman, 1999; Perkins, Borden, Keith, Hoppe-Rooney, & Villarruel, 2003). The authors suggest that opportunities for community participation allow youth to contribute to their own development as well as the development of their communities (Curnan & Hughes, 2002; Perkins, et al., 2003). Such opportunities move youth from a passive to an active role in their own development and may act as stepping stones not only to a sense of belonging within a community (Cargo et al., 2003), but also to a broader awareness and interest in the community at large (Flanagan & Van Horn, 2003).

> Researchers and practitioners use a variety of terms to describe youth engagement,
> - *Youth Action:* concrete actions by young people that make a difference in their lives, their communities, and society as a whole.
> - *Youth Empowerment:* an attitudinal, structural, and cultural process whereby young people gain the ability, authority, and agency to make decisions and implement change in their own lives and the lives of others.
> - *Youth Infusion:* the process of integrating youth into all spheres of community life to ensure their voices and actions are valued and are influential in efforts aimed at social and community change.
> - *Youth Participation:* the process of involving young people in the decisions that affect their lives.
> - *Youth Voice:* the process of integrating young peoples' ideas, opinions, involvement, and initiative into community efforts.

Youth engagement in mental health systems embodies the positive youth development approach. The model views young people as important community resources and partners in change. The closely aligned community youth development model (Perkins at al., 2003) defines community youth development as: "purposely creating environments that provide constructive, affirmative, and encouraging relationships that are sustained over time with adults and peers, while concurrently providing an array of opportunities that enable youth to build their competencies and become engaged as partners in their own development as well as the development of their communities" (Perkins et al., 2003, p.6).

Available literature focuses considerable attention on articulating what defines successful adolescent development and how to support it effectively. Positive youth development is a general approach that emphasizes factors that strengthen youth development. It is a framework for structuring services, systems, and supports so young people develop the knowledge and skills they need to successfully enter adulthood. Some youth-serving organizations, researchers, and clinicians refer to positive youth development in terms of "developmental assets" which are the skills, abilities, and experiences that young people need to become healthy adults. Other definitions of positive youth development emphasize the supports necessary to promote the

development of these assets. The approach posits that young people do not develop assets solely by understanding and avoiding risk factors (Perkins, et al., 2003). They must also have positive opportunities: to participate in nurturing and mutual relationships with adults and peers; to explore talents and interests, developing a sense of competence and personal identity; and to engage in leadership and decision-making, developing a sense of self-efficacy and control over their future.

Through the growing youth engagement movement, young people are being invited to participate as partners in a wide range of community activities, both within and outside of the mental health arena. One of the ways in which this engagement may have a significant impact in the way we think about mental health is through engaging youth as partners in research and evaluation. Terms such as "participatory-action research," "youth participation in community research and evaluation," "youth-led research," "youth-led evaluation," "youth-led research and evaluation," "youth-led mapping," and "community youth mapping" are commonly used. By engaging young people in research and evaluation, the knowledge base is enhanced while youth are provided with opportunities for development and empowerment.

Another form of youth engagement is participating in organizational decision-making and governance. This focuses on the ways young people are involved in decision-making processes within an initiative or organization and includes advising decision makers or being decision-makers. With reasonable accommodations and supports, young people can participate in decision-making in ways that enhance their own personal development and provide valuable insight and contributions to organizations and their communities.

Empirical Support for Youth Engagement

Youth and family involvement is increasingly accepted as a necessary component in all levels of systems work. However, the research base on youth engagement specific to mental health systems of care has only recently begun to receive attention and much of the literature reviewed for this paper comes from the broader positive youth development and youth involvement literature. Within Medicaid mental health systems, a 2006 survey, 21 states reported that they permit Medicaid reimbursement for families working in various practice related roles. For youth, 14 states permit Medicaid reimbursement to youth in service related roles (Cooper, 2008).

> "...young people should grow up in communities, not programs."
> -   NCFY, 1996

As consumers of services, youth play a central role in their own recovery and in the effective functioning of the system of care. According to research by Burns, Hoagwood, and Mrazek (1999, p.238), "…the effectiveness of services, no matter what they are, may hinge less on the particular type of service than on how, when and why families or caregivers are engaged in the delivery of care…it is becoming increasingly clear that family engagement is a key component not only to participation in care, but also in the effective implementation of it." Additional research has emerged to support family involvement as a vital component to effective interventions. Some research goes even further – "not all the studies show that improvements resulted from the intervention specifically. Family engagement (including youth) may play a stronger role in the outcomes than the actual intervention program" (Thomlison, 2003, p.584,

parentheses added for clarity). In addition, consumers and families told the Presidents New Freedom Commission on Mental Health Transformation that, "having hope and the opportunity to regain control of their lives was vital to their recovery. Indeed, emerging research has validated that hope and self-determination are important factors contributing to recovery" (Thomlison, 2003, p.27). These findings coincide with the experiences of many young people. Though we are only in the initial steps in evaluating the effectiveness of youth involvement, there is emerging evidence of the benefits of youth involvement from youth, family, and provider anecdotal stories.

Available research and evaluation studies demonstrate that youth engagement has positive effects on young people and the adults and organizations working with them. These opportunities enable youth to contribute to their own development by applying and learning life skills. In addition, they allow youth to contribute to the development of their communities by designing solutions to address local issues. Involving youth in decision-making also positively affects adults and helps change organizational culture. Examples include:

- Young people who participated in leadership activities reported higher levels of self-efficacy than young people who did not participate in these activities (Edelman, et al., 2004).
- In addition to determining the impact of leadership opportunities on youth, researchers have studied the impact of youth involvement in civic activism. Civic activism was found to be a powerful approach for engaging more vulnerable youth who were not reached by traditional youth development programs. Youth who were interviewed indicated they struggled with the negative public perception of their abilities, limited options, and premature pressures and responsibilities, and that participating in civic engagement gave them a voice to address the issues they related to most (Social Policy Research Associates, 2003). Youth engagement provides opportunities for youth to learn and use new skills that enable them to build competence and confidence.

A recent guide to youth involvement (Matarese, McGinnis and Mora, 2005) conducted a review of available literature and developed a summary list of benefits of youth engagement to youth, families, adults and organizations. The following list of benefits is excerpted directly from their review. While the specific source and level of evidence is not evident for each benefit listed, according to their review, youth engagement helps youth to:

- Understand the community in a different way,
- Make friends,
- Have a support group of people who "get them,"
- Create a positive change in their community,
- Develop new skills and knowledge,
- Reframe their personal identities from an "SED kid" to a leader and change agent,
- See themselves reflected from peers and family members in a positive light,
- Develop confidence and strengthen their sense of pride, identity, and self-esteem,
- Create a better system that will help themselves and others, and
- Have their voice heard and utilized..

A separate study also demonstrated that young people feel more able to control their own lives in a positive way, strengthen their connection to the community, engage in their education, and

avoid risky behavior when they are able to improve the lives of others (Lewis, 2003). Youth engagement helps families to:

- See their sibling or child evolve into a leader with competencies and a sense of belonging, self advocacy, and independence skills,
- See that their children are resilient,
- View the youth as a model for the family for utilizing mental illness as a strength,
- Become more strength-based as they see the youth growing and becoming change agents,
- Gain relief and respite from caregiving, and
- See that the youth has the ability to connect with peers and have sustained relationships.

The same study also showed that youth engagement helps adults to:

- Experience young people's competence,
- View youth as legitimate and essential contributors to the organizational decision-making process,
- Feel more effective, confident, and competent in their work with youth and the work of youth, and
- Gain a stronger sense of community connectedness.

Organizations and staff also benefit from involving young people in decision-making opportunities. In a study conducted by the National 4-H Council (Zeldin, McDaniel, Topitzes, & Calvert, 2000), researchers found that youth involvement in organizational decisions helps in a variety of ways. Youth engagement helps organizations:

- Bring clarity to their mission,
- Improve adult staff involvement,
- Enhance their responsiveness to the community,
- Strengthen their commitment to the work,
- Raise funds,
- Better meet the needs of young people when they understand youth,
- Enhance the commitment and energy of adults,
- Embed youth involvement principles in the organization practices,
- View the importance and benefits of involving a diverse community in decision making,
- Generate increased creativity, and
- Bring underrepresented groups into organizational decision making.

Planners and policymakers benefit from youth involvement and can utilize the expertise of young people to enhance youth-serving systems. Youth involvement helps planners and policymakers:

- Develop a better understanding of the needs and issues of the youth population they serve,
- Gain a different perspective of youth experiences with multisystem involvement,
- Develop systems that are more creative and better meet the needs of children and families, and
- Know what works and does not work based on real world youth experience.

Youth involvement helps the community:

- Interact with youth to overcome youth culture stereotypes,
- Increase its understanding of how young people view the world,

- Identify ways to enhance their community,
- Generate fresh and innovative ideas of young people,
- Increase community relations, and
- Increase youth ability to make positive contributions to the community.

In all, the available literature suggests that youth engagement is a critical component to effective systems of care. The empirical base for youth engagement in systems of care is limited but growing. The results from available literature are, however, encouraging. Youth participation in increasingly valued by youth, caregivers, providers and policy makers and may improve the developmental and emotional functioning of youth.

References

Cargo, M., Grams, G., Ottoson, J., Ward, P., & Green, L. (2003). Empowerment as fostering positive youth development and citizenship. Journal of Health Behavior, 27, S66-S79.

Curnan, S. P., & Hughes, D. M. (2002). Towards shared prosperity: Changemaking in the CYD movement. Community Youth Development Journal, 3, 25-33.

Edelman, A. Gill, P., Comerford, K., Larson, M., & Hare, R. (2004) Youth Development and Youth Leadership (Washington, D.C.: National Collaborative on Workforce and Disability for Youth,). Available at: <http://www. ncwdouth.info/assets/background/YouthDevelopment.pdf>.

Fischhoff, B., Crowell, N., & Kipke, M. (Eds.). (1999). Adolescent decision making: Implications for prevention programs: summary of a workshop. Washington, DC: National Academy Press.

Flanagan, C. & Van Horn, B. (2003). Youth civic development: A logical next step in community youth development. In Villarruel, F. A., Perkins, D. F., Borden, L. M., & Keith, J. G. (Eds.), Community Youth Development: Programs, policies, and practices (pp. 201-223). Thousand Oaks, CA: Sage Publications.

Gray, A, & Hayes, C. (2008). Understanding the State of Knowledge of Youth Engagement Financing and Sustainability. The Finance Project. Washington DC.

Hoagwood, K. E., Green, E., Kelleher, K., Schoenwald, S., Rolls-Reutz, J., Landsverk, J., Glisson, C., & Mayberg, S. (2008). Family Advocacy, Support and Education in Children's Mental Health: Results of a National Survey. Admin Policy Mental Health, 35, 73 - 83.

Huff, B., (1998). Federation celebrates 10 year anniversary. Claiming Children, Spring 1998.

Hyman, J. B. (1999). Spheres of influence: A strategic synthesis & framework for community youth development. Baltimore, MD: The Annie E. Casey Foundation.

Lewis, A. (Ed.). (2003). Shaping the future of American youth: Youth policy in the 21st century. Washington, DC: American Youth Policy Forum. Retrieved on October 29, 2004, from http://www.aypf.org/publications/shaping_future_youth.pdf.

Matarese, M., McGinnis, L., & Mora, M. (2005) Youth Involvement in Systems of Care: A Guide to Empowerment. Technical Assistance Partnership. TAPPublications@air.org

Perkins, D. F., Borden, L. M., Keith, J. G., Hoope-Rooney, T. L., & Villarruel, F. A. (2003). Community youth development: Partnership creating a positive world. In Villarruel, F. A., Perkins, D. F., Borden, L. M., & Keith, J. G. (Eds.), Community Youth Development: Programs, policies, and practices (pp. 1-24). Thousand Oaks, CA: Sage Publications.

Perkins, D. F., Borden, L. M., Keith, J. G., Hoope-Rooney, T. L., & Villarruel, F. A. (2003). Community youth development: Partnership creating a positive world. In Villarruel, F. A., Perkins, D. F., Borden, L. M., & Keith, J. G. (Eds.), Community Youth Development: Programs, policies, and practices (pp. 1-24). Thousand Oaks, CA: Sage Publications.

Polz, B. (2000). A youth development structural perspective. Academy for Educational Development. Center for Youth Development. Washington DC.

Search Institute, The Power of Youth and Adult Partnerships and Change Pathways for Youth Work—Executive Summary (Battle Creek, Mich.: W. K. Kellogg Foundation, 2005). Available at: <http://www.search-institute.org/research/KelloggExecSummary.pdf>.

Social Policy Research Associates, Lessons in Leadership: How Young People Change Their Communities and Themselves (Takoma Park, Md.: Innovation Center for Community and Youth Development December 2003).
<http://www.theinnovationcenter.org/pdfs/Lessons_in_Leadership_exec.pdf>.

Zeldin,S. McDaniel, A.Topitzes, D. and Calvert, M. (2000) Youth in Decision-Making: A Study on the Impacts of Youth on Adults and Organizations (Chevy Chase, Md.: Innovation Center for Community and Youth Development and National 4-H Council). Available at: <http://www.cpn.org/topics/youth/cyd/pdfs/Youth_in_Decision_Making.pdf>.

Appendix Five – The History and Evidence Base for Services and Supports from Adult Family Member Organizations

Current approaches to the provision of mutual support, empowerment and activism by family members of adult consumers have evolved out of a long and difficult relationship with the mental health care system (Gubman and Riesser, 1994). From the 1880s until the 1970s, clinical theories and practices often excluded families from care or blamed them for their family member's mental illness. With the introduction of major neuroleptic medications in the 1950s, it was expected that people formerly institutionalized in large psychiatric hospitals could be stabilized in community-based mental health programs. As this process unfolded, families had increasing responsibility in caring for relatives with mental illness at home.

The passage in 1963 of the Community Mental Health Services Act deinstitutionalized mental health consumers, mandating treatment in the least restrictive environment and extending some hope of support to mental health consumers and their families (Grubman and Riesser, 1994). However, families' needs were not adequately anticipated or met, which resulted in significant hardships for families. Hospital stays tended to be shorter and more frequent; development of community supports and services lagged behind proposed levels; and families received little or no preparation, support or information to address instances of decompensation and increased symptoms in their relatives (Grubman and Riesser, 1994).

History of the National Alliance on Mental Illness (NAMI)

By the early 1970s, concerned family members around the country, responding to increased family burden and fragmented or unavailable professional support (and influenced by the self-help movement), began reaching out to each other. A group from San Diego, California calling themselves "Parents of Adult Schizophrenics" began meeting around their kitchen tables to offer each other support during this era when "parents were thought to be the cause of their children's mental illness" (NAMI San Diego's History, 2007). In 1974, a group of concerned parents of adult children with mental illness founded the support group "Oasis Fellowship" in Lansing, Michigan, with additional independent family support groups forming independently over the next few years throughout that state (Huebel, 2006).

In 1978, a community tragedy in Seattle led to the formation of Washington's first support group for family members of adult consumers. A young man with severe mental illness took the lives of two elderly neighbors; his parents' prior attempts to have him hospitalized had been denied because he did not meet criteria for dangerousness. Eight "strangers" – all parents of adult children with severe mental illness – spontaneously reached out to this young man's parents. Within a week of the tragedy, the Washington Advocates for the Mentally Ill (WAMI) was founded. Following this, members of various family support groups from across the nation (including key members from WAMI) made contact with each other, eventually leading to the decision to form a national group to support and advocate for individuals and families living with severe mental illness. In September 1979, approximately 250 family members from seven states – California, Florida, Maryland, Missouri, New York, Wisconsin and Washington – met in Madison, Wisconsin and founded the National Alliance for the Mentally Ill (now called the National Alliance on Mental Illness). In its early years, NAMI chiefly relied upon its volunteers

for funding, dissemination of information and advocacy work. By 1980, they were able to secure $75,000 in funding from the National Institute of Health, which helped them establish their first office in the Washington, D.C. area (Owen, October 2008, Personal Communication).

NAMI's membership and influence has grown considerably over the last thirty years; it is now the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. Comprising over 1,100 affiliates in local communities in every state, NAMI serves over 200,000 members (National Alliance on Mental Illness [NAMI], 2007; Office of the Surgeon General, 1999). To fulfill its mission of eradicating mental illnesses and improving the quality of life of all who are affected by these diseases, NAMI has developed a wide array of activities, including (NAMI, 2007b):

- **Family and consumer peer education and support** – In 2007, the Family-to-Family program trained 138 new teachers nationwide (23 of whom are Spanish-speaking) and has 130,000 graduates in 48 states; the Peer-to-Peer program, available in 32 states, trained 177 new mentors and graduated 343 participants; and Provider Education was offered in 21 states, with 10,000 graduates and 940 teachers trained to date.
- **Public education and information** – Over 19,000 visitors a day access NAMI's website for information and referral sources; their HelpLine fields over 4,000 calls a month; public awareness activities include Mental Illness Awareness Week, the StigmaBusters network, and In Our Own Voice; and their membership magazine, The Advocate, provides current reports on advocacy, legislation, medical care, and research.
- **Advocacy on behalf of people living with mental illness** – Advocacy efforts take place on the national, state and local levels, including the "Grading the States" report, which advocates for higher standards for developing public mental health services in the United States, and Action Centers, which advocate for special populations and advances information to meet specific needs.
- **Public events that raise funds and awareness** – NAMIWalks attracts thousands of concerned citizens in over 70 communities across the nation to walk in support of raising funds and awareness, raised nearly $7 million nationwide in 2007.

NAMI in Washington State

There are NAMI affiliates across Washington State, and NAMI Washington provides a statewide voice for those affiliates. To illustrate the impact of NAMI affiliates in Washington over time, this review focuses on NAMI Greater Seattle, the longest standing of the affiliates. However, it should be kept in mind that there are 23 NAMI affiliates across the state, including NAMI Chelan / Douglas, NAMI Citizens Guild of Western, NAMI Clallam County, NAMI Cowlitz, NAMI Eastside, NAMI Jefferson County, NAMI Kitsap County, NAMI Kittitas County, NAMI Lewis County, NAMI North Sound, NAMI Palouse, NAMI Pacific County, NAMI Skagit, NAMI Snohomish County, NAMI Spokane, NAMI Thurston/Mason, NAMI Tri-Cities, NAMI Walla Walla, NAMI Washington Coast, NAMI Whatcom, NAMI Whidbey Island, and NAMI Yakima. Each of these affiliates provides an array of supports that vary by locale and include family support groups, as well as empirically-supported programs like Family-to-Family (discussed in more detail later in this appendix). In addition, NAMI Washington and the local affiliates provide an array of advocacy and local supports, such as support by NAMI Washington for statewide development of Program for Assertive Community

Treatment (PACT) teams, statewide efforts to combat criminalization of mental illness in partnership with the GAIN Center, Crisis Intervention Team (CIT) training for local law enforcement in many communities, NAMI Eastside's support and development of a local clubhouse program (Hero House).

In order to show how local NAMI affiliates develop and support the broader mental health system in their home communities, this appendix looks in more depth at NAMI Greater Seattle. As noted above, NAMI Greater Seattle (originally called the Washington Advocates for the Mentally Ill – WAMI) began in 1978 when eight strangers, responding to a local tragedy, "came together to see what they could do to inform the public, influence the legislature, and support those who struggle with mental illness, their families and friends." During that first year, similar support groups formed in multiple counties across Washington, and WAMI hosted the first Washington State Conference on Chronic Mental Illness (NAMI Greater Seattle, 2008).

Grassroots support played a significant role in WAMI's initial efforts. Families with children with developmental disabilities who had significant experience with advocacy, raising awareness, and negotiating systems of care served as an invaluable resource to the founding members of WAMI. Within a week of their first meeting, WAMI drafted an amendment to the Involuntary Treatments Act (RCW 71.05), "focusing on the earliest, obvious symptoms of 'grave disability due to a mental illness' as legal criteria for a 72-hour evaluation." This amendment was passed in 1979. During the 1980's, WAMI saw further growth. In 1982, the Downtown Emergency Service homeless shelter was started with just $90; by 1990 this service had assets of $63 million (Owen, October 2008, Personal Communication). In 1983, WAMI was admitted as a United Way funded agency and by 1985 it began receiving funding from the Washington State Legislature (NAMI Greater Seattle, 2008).

In 1996, WAMI was recognized by NAMI's national organization as its largest affiliate. Also during that year, WAMI influenced the State Legislature to sponsor SB 5995, which mandated non-discriminatory health insurance. In 1999, Hofmann House for Men was developed as a unique partnership between WAMI and six men coping with severe mental illness. With a $100,000 donation from a WAMI member, an older home was purchased and these men, who for much of the preceding twenty years had been incarcerated, hospitalized or homeless, received training in renovating the home. Upon completion of the project, all six men moved in and assumed rent payment, upkeep and maintenance. Since 2000, none of the men have been incarcerated and only one was briefly hospitalized (NAMI Greater Seattle, 2008).

By 2002, WAMI acknowledged its standing as an affiliate of NAMI's national organization and changed its name to NAMI Greater Seattle. In 2007, Hofmann House for Women, modeled after Hofmann House for Men, was completed with support from individual and corporate donors and is now home to five women with severe mental illness. Currently, NAMI Greater Seattle provides a wide array of services and supports to individuals and families affected by mental illness, which in 2007 included (NAMI Greater Seattle, 2008):

- 4,394 person-to-person contacts for advocacy, crisis intervention support, information and referral,
- Permanent housing for eleven people,

- 301 self-help group meetings (25 sessions a month), with 1,590 people attending,
- 116 educational sessions with 2,627 people attending, including public forums and programs such as Family-to-Family, Speakers Bureau, In Our Own Voice, and Educating the Next Generation, and
- 5,827 newsletters ("Spotlight") distributed.

Additional services NAMI Greater Seattle offers include ongoing advocacy and testimony before the State Legislature and the publication "Connections: A Self-Help and Resource Guide for Individuals with Mental Illness, Their Families and Social Service Providers", which is a comprehensive guide to understanding mental illness and navigating the mental health system (Owen, October 2008, Personal Communication).

Evidence Base of Services and Supports by Family Members of Adult Consumers of Mental Health Services

A broad array of research has shown that outcomes for people with severe mental illness improve when the needs of family members for information, clinical guidance, and support are met (Dixon, McFarlane, Lefley et al., 2001). Two models that have been developed to address the needs of families of individuals with mental illness are family psychoeducation and Family to Family education.

Family Psychoeducation

Family psychoeducation is a method of working in partnership with families to provide current information about mental illness and to help families develop increasingly sophisticated coping skills for handling problems posed by mental illness in one member or the family (SAMHSA, 2003). These programs last from nine months to five years, are usually diagnosis specific, and focus on both consumer outcomes directly and the well-being of family members in support of those outcomes (Dixon, McFarlane, Lefley et al., 2001). Under these approaches, the practitioner, consumer, and family work together to support recovery, incorporating individual, family, and cultural realities and perspectives.

Family psychoeducation can be used in a single family or multi-family group format and can vary in terms of the duration of treatment, consumer participation, and treatment setting, depending on the consumers and family's wishes, as well as empirical indications. Although several treatment models exist, the following are essential elements of any evidence-based program (see McFarlane, Dixon, Lukens and Lucksted, 2003):
- The intervention should span at least nine months.
- The intervention should include education about mental illness, family support, crisis intervention, and problem solving.
- Families should participate in education and support programs.
- Family members should be engaged in the treatment and rehabilitation of consumers who are mentally ill.
- The information should be accompanied by skills training, ongoing guidance about management of mental illness, and emotional support for family members.
- Optimal medication management should be provided.

Extensive research demonstrates that family psychoeducation significantly reduces rates of relapse and re-hospitalization. When compared to consumers who received standard individual services, differences ranged from 20 – 50% over two years (Penn and Mueser, 1996; Dixon and Lehman, 1995; Lam, Kuipers and Leff, 1993; and Falloon, Held, Coverdale et al, 1999; as cited by Dixon, McFarlane, Lefley et al, 2001). Recent studies have shown employment rate gains of two to four times baseline levels, especially when combined with supported employment, another evidence based practice. Families report a decrease in feeling confused, stressed, and isolated, as well as experience reduced medical care costs. In addition, studies consistently indicate a very favorable cost-benefit ration, especially in savings from reduced hospital admissions, reduction in hospital days, and in crisis intervention costs.

The SAMHSA/CMHS Family Psychoeducation Resource Kit suggests that family psychoeducation is most beneficial for people with the most severe mental illnesses and their families. Although most research involves consumers with schizophrenia, improved outcomes have been found with other psychiatric disorders, including bipolar disorder, major depression, obsessive-compulsive disorder, anorexia nervosa, and borderline personality disorder (as cited in Dixon, McFarlane, Lefley et al, 2001).

Family-to-Family Education Program

Family psychoeducation has been recognized as an evidence based practice for reducing hospitalization, but it has also been reported that these programs have not been widely available due to barriers of dissemination and adoption (Dixon, McFarlane, Lefley et al, 2001). To fill this gap, family- and peer-based education programs have emerged to provide important resources to family members of people with severe mental illness (Dixon, Stewart, Burland et al, 2004).

While family education shares many of the characteristics of family psychoeducation (e.g., providing education and support, promoting effective coping), there are clear differences between these two approaches, including family education programs' shorter duration, reliance on family peer facilitators, and focus on the well-being of the family as primary outcomes (Dixon, Stewart, Burland, Delahanty, Lucksted and Hoffman, 2001). The Family-to-Family Education Program (originally called Journey of Hope), sponsored by NAMI and developed in 1991 by NAMI member, Joyce Burland, is one of the most widely disseminated programs of this type.

The Family-to-Family Education Program (FFEP) is a free, 12-week course for family caregivers of individuals with severe mental illnesses. Based on a trauma-recovery model of a family's experience of living with mental illness, FFEP merges education with specific support strategies to help families develop understanding and effective coping skills (Dixon, McFarlane, Lefley et al, 2001). The course is taught by trained family members of individuals with mental illness and covers the following curriculum (NAMI, 2008b):
▪ Presents current information about major mental illnesses and co-occurring brain disorders and addictive disorders,

- Provides current information about medications, research related to the biology of brain disorders, and evidence-based, most effective treatments to promote recovery,
- Facilitates empathy by understanding the subjective, lived experience of a person with mental illness,
- Teaches coping strategies, problem solving and communication techniques,
- Focuses on care for the caregiver, including coping strategies for worry, stress and emotional overload, and
- Facilitates information/referral services and access to advocacy initiatives within the community.

Unlike family psychoeducation, rigorous research documenting the effectiveness of peer-based family education in general and FFEP in particular is just starting to emerge (Dixon, Lucksted, Stewart, Burland et al, 2004). A 1997 program evaluation of FFEP conducted in three states indicated high satisfaction rates, increased knowledge of mental illness, improved management of their ill relative's behavior, and increased awareness of the mental health system among participants (Pickett, Cook and Laris, 1997, as cited by Dixon et al, 2004). In 2001, a pilot study undertaken to assess the efficacy of FFEP showed that participants who completed the program demonstrated significantly greater family, community, and service system empowerment, and reduced displeasure and worry about their family member who had a mental illness (Dixon, Stewart, Burland, Delahanty, Lucksted and Hoffman, 2001).

Dixon, Lucksted, Stewart, Burland, Brown, Postrado, McGuire, and Hoffman (2004) followed up the 2001 pilot study with a controlled evaluation of the effectiveness of FFEP. This study recruited subjects who had signed up for FFEP and were placed on a three month waiting list. Ninety-five subjects were assessed at four intervals: three months prior to starting FFEP, at the start of FFEP, immediately after FFEP, and six months after completing the program. Assessments measured subjective burden (worry and displeasure), depression, self-esteem, mastery, and empowerment in three domains (family, community and system). Results showed that after attending the FFEP, participants' self-reported subjective burden was significantly reduced, their level of empowerment in all three domains was greatly enhanced, and depression symptoms were significantly improved. They also found that gains evident at the end of this brief program were sustained for at least six months after completion. The authors determined that this study strengthens the available evidence that NAMI-sponsored FFEP meets its stated goals of reducing subjective burden, increasing empowerment, increasing knowledge of mental illness and the mental health system of care, and increasing self-care among family members of people with severe mental illness, and suggest that this study provides a solid first step on the way to recognizing FFEP as an evidence-based practice for assisting family members.

A current study by researchers at the University of Maryland School of Medicine "could put Family To Family more prominently 'on the map' as an emerging evidence-based practice" (Lucksted, Hawes, and Dixon, 2007). Through a $2.2 million grant awarded in 2005 from the National Institute of Mental Health (NIMH), this research team is conducting a larger, scientifically rigorous, and comprehensive study with NAMI of the benefits of FFEP (NAMI, "Family to Family", 2008). Participants in the study will be randomly assigned to either an intervention group (FFEP) or a comparison group (delayed FFEP for three months). Data

collection began in 2006, starting with four NAMI affiliates. This study will span four years (Lucksted, Hawes, and Dixon, 2007).

Other aspects of FFEP identified as requiring further study include a closer examination of differential responses between parents and non-parent family members and an exploration of differences in responses between racial and ethnic groups (Dixon, Lucksted, Stewart, Burland et al, 2004). In addition, it has been noted that further studies are needed to identify effective "dose" levels of family psychoeducation, address differences in families at different phases of illness, and clarify ways to effectively remove barriers to implementing these programs (Dixon, McFarlaen, Lefley,et al, 2001).

References

Dixon, L., Lucksted, A., Stewart, B., Burland, J., Brown, C.H., Postrado, L., McGuire, C., and Hoffman, M. (2004). Outcomes of the peer-taught 12-week family-to-family education program for severe mental illness. *Acta Psychiatrica Scandinavica*, 109: 207 – 215. Retrieved on October 3, 2008 from http://www.nami.org/Content/ContentGroups/Programs/Family_to_Family/WaitlistStudyActa Article.pdf

Dixon, L., McFarlane, W., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., Mueser, K., Miklowitz, D., Solomon, P., & Sondheimer, D. (July 2001). Evidence-based practices for services to families of people with psychiatric disabilities, *Psychiatric Services*, 54 (7), 903 – 910. Retrieved on October 2, 2008 from http://psychservices.psychiatryonline.org/cgi/reprint/52/7/903.pdf

Dixon, L., Stewart, B., Burland, J., Delahanty, J., Lucksted, A., & Hoffman, M. (July 2001). Pilot study of the effectiveness of the family-to-family education program. *Psychiatric Services*, 52 (7), 965 – 967. Retrieved on October 2, 2008 from http://psychservices.psychiatryonline.org/cgi/reprint/52/7/965

Gubman and Riesser. (1994). Relationships between Family Caregivers and Mental Health Professionals: The American Experience. In Lefley, H. and Wasow, M. (Eds). *Helping families Cope with mental illness*, New York: Harwood Academic Publishers.
Downloaded from http://books.google.com/books?id=rgTRTHkCWboC&pg=PA131&lpg=PA131&dq=Helping+ Families+Cope+with+Mental+Illness,+Lefley,+Wasow&source=web&ots=A4gavFQpHf&sig =lhitwO4v9TGcJKvyLgg7VtGZK4A&hl=en&sa=X&oi=book_result&resnum=1&ct=result

Huebel, H. (2006). An updated history of NAMI Michigan. Retrieved October 3, 2008 from the NAMI Michigan Web site: http://mi.nami.org/HISTORYHH2.htm

Lucksted, A., Hawes, R., and Dixon, L. (2007). Investigating the evidence-base for NAMI's family-to-family and peer-to-peer programs. *NAMI Advocate*, Winter 2007, 1 – 4. Retrieved on October 3, 2008 from

http://www.nami.org/Content/ContentGroups/Advocate/Winter_2007/Advoc_wntr07-F2F_article.pdf

Lucksted, A., Stewart, B., & Forbes, C. (September 2005). Benefits and changes for Family to Family graduates, *American Journal of Community Psychology*, 42(1-2), 154 – 166. Retrieved October 3, 2008 from http://www.nami.org/Content/Microsites180/NAMI_Dallas_Inc_/Home167/Programs83/Education_Programs3/Family_to_Family11/Teacher_Resources1/2008update_article.pdf

NAMI Greater Seattle. (2008). *About NAMI Greater Seattle*. Retrieved October 3, 2008 from the NAMI Greater Seattle Web site: http://www.nami-greaterseattle.org/about.htm

NAMI Greater Seattle Annual Report 2007. (2008, July/August). [Electronic version]. Spotlight, pg 4. http://www.nami-greaterseattle.org/files/spotlight/0807.pdf

NAMI San Diego. (2007). *NAMI San Diego's history* Retrieved October 3, 2008, from the NAMI San Diego Web site: http://www.namisandiego.org/history.php

National Alliance on Mental Illness (NAMI). (2007a). *2007 Annual Report*. Retrieved on October 5, 2008 from the NAMI Web site: http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_NAMI/Annual_Reports/2007NAMIannualReport.pdf

NAMI. (2007b). *NAMI Factsheet*. Retrieved October 4, 2008 from the NAMI Web Site: http://www.nami.org/Template.cfm?Section=About_NAMI&Template=/ContentManagement/ContentDisplay.cfm&ContentID=58580

NAMI. (2008a). *About NAMI*. Retrieved October 3, 2008 from the NAMI Web site: http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_NAMI/About_NAMI.htm

NAMI. (2008b). *NAMI Family-to-Family*. Retrieved on October 5, 2008 from the NAMI Web site: http://www.nami.org/Template.cfm?Section=Family-to-Family&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=4&ContentID=66949

U. S. Department of Health and Human Services, Office of the Surgeon General. (1999). *Mental health: A report of the Surgeon General - Overview of consumer and family movements*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental. Retrieved on September 30, 2008 from http://www.surgeongeneral.gov/library/mentalhealth/chapter2/sec9.html

Appendix Six – Examples of Consumer and Family Run Services and Supports

Members of the Work Group took the lead in developing a broad overview of the types of services and supports that should be available. The summary began with an initial list developed during the first Work Group meeting in late April, then incorporated a review of the input of consumers and family members provided in previous initiatives such as the 2007 System Transformation Initiative, the 2007 and 2008 forums related to SHB 1088, and additional data from youth reviewed in collaboration with Youth N' Action. This information concluded that possible supports include mutual support, community building, a wide array of specific services and supports, and advocacy. This information was incorporated as follows:

- Raw data from the consumer and family member focus groups conducted in early 2007 for the System Transformation Initiative[8] was reviewed and incorporated into the original list developed by the Work Group in April. The raw data was reviewed to ensure that the consumer and family input was appropriately included.
- Work Group members that had participated in the SHB 1088 community forums reviewed the summary to ensure that input from that process (which has not yet been published) was incorporated based on the perspectives of those participants.
- Findings from a recent study of the perspectives of a diverse array of youth consumers, including a large sample of African American youth, were incorporated.[9]

One important point stressed by multiple consumer and family informants was the importance of the fit between the experience of the people who work at the consumer or family run organization and the people they serve. The field review draft of the federal Center for Mental Health Services (CMHS) Consumer-Oriented Services Program (COSP) Evidence-Based Practice (EBP) Kit addresses this issue well (CMHS, 2007),[10]

> *By definition, peer support happens among individuals who share common experiences. If you are designing a peer support service for people going through marital difficulties, then yes, that person could be considered a peer or consumer. However, if you are establishing a COSP for persons who have experienced problems with serious mental illnesses, then a person with only marital counseling experience would not be the right person to run it. (CMHS, 2007, Section 4, page 6)*

The following table summarizes the array of services and supports identified. It should be noted that this table is not intended to be an exhaustive summary of all possible consumer and family run services and supports. As discussed above, the diversity of consumer and family run services is continually expanding as new organizations and opportunities emerge. The table is instead offered to illustrate the broad array of services and supports that can be delivered and which any future certification standards for consumer and family run organizations must be able to accommodate and support. In reviewing these, the Work Group noted that cultural

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[8] See Appendix Three of the following report for a summary of the focus group findings: TriWest Group. (July, 2007). *Statewide Transformation Initiative Mental Health Benefit Package Design Final Report.* Previously cited.
[9] Need to add citation for Tamara's study
[10] Previously cited.

competency is a cross-cutting principle that must be applied to all of these services and supports.

Examples of Service and Support provided by Consumer and Family Run Organizations
Examples Appropriate for Consumers (Youth, Adults, Older Adults), Parents, Caregivers, and Other Family Members
Advocacy Services at both the Individual and System Levels
Benefit Planning and Navigation
Brokerage / Self Directed Supports
Budgeting and Saving Programs
Community Centers / Drop in Centers
Community Service Opportunities to Give Back and Help Others
Education / Training Responsive to Local Needs
Employment
Health / Wellness/ Smoking Cessation
Hospital Transition/Community Re-entry
Housing
Information & referral to concrete services
Learning Academies
Legal Clinics
Mutual Support Groups
Ombuds Services
Peer Advocate / Upfront Navigator
Peer Support and Peer Support Training in Inpatient and Outpatient Settings
Peer Support for managing ineffective mental health service providers
Prevention and Intervention
Psychiatric Services Delivered by Consumer and Family Run Organizations
Psychoeducation
Referral to Other Services (professional, community)
Resource / Support Groups and Coordinators
Respite
Self Advocacy Training
Self Help Centers
Social / Recreational
Transportation
Warm Line
Youth-Guided, Consumer-run Program Evaluation
12 Step Groups
Substance Abuse Services
Clinical Specialists
Wellness Recovery Action Plans
Examples Appropriate for Consumers (Youth, Adults, Older Adults)
Anti-Stigma Campaigns
Community Gardening

Examples of Service and Support provided by Consumer and Family Run Organizations
Crisis Services (consumer run)
Development of communities in which the individual engages in social interactions and gains goods and services to achieve social and economic well-being
Jail / Hospital Diversion
Supported Education for Finishing High School
Supported Education Programs for College
Transitional Services (including help with housing, employment and acquiring effective concrete services)
Treatment Groups
Examples Appropriate for Youth and Their Families
Life Skills Training
Resiliency Support
School Support, Special Education (IDEA, 504)
Transition Age Community Centers
Wraparound and Wraparound-type Services, including Transition Age Wraparound
Examples Appropriate for Older Adult Consumers and Their Families
Retirement Center for People with Disabilities

Appendix Seven – Potential Sources of Funding and Resources

Type of Funding[11]	Examples and Requirements
Local Funding Sources and Resources	▪ Fund Raising – Fund raisers, like garage sales, auctions and other homegrown funding efforts, can help lay a framework for groups starting out. ▪ In Kind Donations – In-kind donations and services from local organizations can also play an important role in initial funding, as well as a catalyst for more global funding efforts. ▪ Utilizing resources and assets within the organization – Skill sets and expertise among staff and board members can defray costs and expand resources. ▪ Strategic partnerships with local and state organizations – Contractual and in-kind partnerships can be developed for mutual advantage. ▪ 1/10 of 1% Tax – Local communities can decide to fund local human service priorities with these funds. ▪ Profit Making Initiatives and Social Enterprises – Organizations can develop profit making enterprises to support service and support programs. ▪ Membership Fees – Members of consumer and family run organizations can contribute directly to their organization. ▪ Volunteers – Enlisting volunteers can enhance community ties, help advertise services and save money on needed services and fundraising activities. Volunteer resources include the Volunteer Centers of Washington and Volunteer Match - two web-based resources for organizations seeking volunteers and volunteers seeking opportunities to serve. ▪ Local service groups, such as Rotary and Lions Clubs, Junior League and Giving Circles – Local service groups generally offer a relatively uncomplicated process for seeking funding. Also, developing relationships with these groups can help build community support. ▪ The Nonprofit and Philanthropy Resource Center – Located in the Redmond Regional Library, this resource center provides a wide range of information related to fundraising, foundations, grants, etc. (all of their resources are available online at www.kcls.org/philanthropy). ▪ Funding from pharmaceutical companies – This can support local activities, particularly for specific events or projects.

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[11] Many of the funding ideas in this table came from the following two sources:
- ▪ Washington's Mental Health Transformation Project. (n.d.). *Funding the consumer run organization.* Retrieved September 14, 2008 from http://mhtransformation.wa.gov/pdf/mhtg/FundingCROs.pdf
- ▪ Centers for Mental Health Services (November, 2007). Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Type of Funding[11]	Examples and Requirements
Federal Block Grant Funding	Flexible funding able to support a wide array of consumer and family organizations and their activities. These funds are administered through RSNs and MHD. The National Outcomes Measures (NOMS) established by SAMHSA support the use of federal Block Grant funds to support consumer and family run organizations.
Federal Medicaid Funding	Medicaid only funds medical services, as discussed in more detail in later sections. As such, only well defined services recognized in the Medicaid State Plan (such as peer support) or in the current 1915(b) Waiver (such as respite or supported employment) can be paid for by Medicaid. Furthermore, these services can only be paid for by Medicaid if the changes discussed further in Sections 5 and 6 of the report are made.
Federal Mental Health Transformation Grant	This five year federal grant entering its fourth year funds pilot projects that are time limited and that respond to the priorities in the State Transformation Plan and the Governor's budget.
Federal Funding from Other Agencies / Resources	▪ Veterans Administration – Must support services and supports to veterans. ▪ Social Security Administration – Can fund supports related to benefit acquisition and outreach. ▪ The National Institute of Mental Health – Can fund consumer and family evaluation and research. ▪ The U.S. Department of Health and Human Services – This is the largest grant-making agency in the federal government, and the Substance Abuse and Mental Health Services Administration (SAMHSA) is a subdivision of this department. SAMHSA funds multiple consumer and family run organizations and technical assistance centers.
State Funding Through RSNs	Funds services to people meeting local access criteria. Can fund a flexible array of services as prioritized on an annual basis by each RSN.
State Funding Through Other State Agencies	Multiple other state and local government agencies can potentially benefit from consumer and family run services, including child welfare, developmental disabilities, juvenile justice, substance abuse, and vocational rehabilitation.

Other Sources	▪ Funding from State Foundations – Some local and regional grant-makers include:
	  o The Catherine Holmes Wilkins Foundation – Serving the Puget Sound area, this foundation includes grants for social services to people with mental illness.
	  o The Kongsgaard Goldman Foundation – A regional foundation, they offer grants in the areas of human rights and civic development.
	  o The M.J. Murdock Charitable Trust –A regional foundation, they provide grants in the area of health and human services, especially focused on youth.
	  o The Medina Foundation – Serving the Greater Puget Sound

Type of Funding[11]	Examples and Requirements

	counties, this foundation includes grants in the areas of disabilities services, family support, housing and homelessness, substance abuse treatment, youth development and others.
	
	   o The North West Health Foundation – Covering the southwest Washington area, this foundation offers three funding programs in the mental health area – Community Grants, Helping Hands Small Grants and Kaiser Permanente Community Fund grants.
	
	   o The Norcliffe Foundation – From the Puget Sound area, this foundation offers grants in the areas of health, social services, civic improvement and youth programs.
	
	  ▪ Funding from National Foundations – Some national non-governmental foundations include:
	
	   o The Ittleson Foundation – Since 1932, mental health has been a major focus for this foundation.
	
	   o The Arca Foundation – Their grant-making tries to "inform and empower citizens" and "mobilize grassroots supports for changing the status quo".
	
	   o The Frank Stanley Beveridge Foundation – This foundation provides grants in the areas of housing, human rights, mental health, crisis intervention and youth development.
	
	   o The William Bingham Foundation – This foundation offers grants in the areas of health and human services.
	
	   o The Do Right Foundation – This foundation provides grants in the areas of fighting joblessness, encouraging transition from welfare to work and improving the lives of children.
	
	   o The John D. and Catherine T. MacArthur Foundation - Their Program on Human and Community Development supports work in community development, youth development and mental health.
	
	   o The Norman Foundation – This foundation offers grants in the areas of civil rights, individual liberties and economic justice[8].
	
	  ▪ Funding from Local Charitable Sources (United Way, Community Foundations, Corporate Giving Programs, Faith-based Organizations)
	
	  ▪ Philanthropy Northwest – This resource includes organizations and individuals ranging from small family foundations to corporate giving programs that fund in Alaska, Idaho, Montana, Oregon, Washington and Wyoming.

Appendix Eight – Technical Assistance Resources

Technical Assistance Resources
Youth and Family Technical Assistance Centers
Statewide Action for Family Empowerment of Washington (www.safewashington.org)
Youth 'N Action (www.YouthNAction.org)
National Technical Assistance Center for Children and Families (http://www.acf.hhs.gov/programs/cb/tta/ntaccmh.htm)
National Alliance on Mental Illness (www.nami.org)
Federation of Families for Children's Mental Health (www.ffcmh.org)
National Consumer Technical Assistance Centers
DBSA Peers Helping Peers Center (www.peerhelpingpeers.org) – Information and technical assistance available, particularly regarding peer specialists
National Consumer Supporter Technical Assistance Center (www.ncstac.org) – Particular expertise on non-profit management development
National Empowerment Center (www.power2u.org) – Particular expertise in organizing statewide groups
National MH Consumer Self Help Clearinghouse (www.mhselfhelp.org) – Can provide range of information on starting peer-run services
STAR Center (www.consumerstar.org) – Focus on cultural adaptation of peer support
Model State-Level Technical Assistance Centers
Collaborative Support Programs of New Jersey (www.cspnj.org)
Georgia MH Consumer Network (www.gmhcn.org)
Involved Consumer Action Network of PA
Mental Health Empowerment Project (NY) (www.mhepinc.org)
On Our Own of Maryland (www.onourownmd.org)
United Advocated for Children and Families (www.uacf4hope.org)
Organizations Supporting Range of Non-Profit Organizations
Executive Service Corps of Washington (www.escea.org) – Broad range of assistance at leadership level, including trainings for board members and staff and high quality consulting
National Center on Nonprofit Enterprise (www.nationalcne.org) – National organization; focused on fiscal strategy
Technical Assistance for Community Services (www.tacs.org) – Offers a wide variety of technical assistance, including training on non-profit capacity development
The Nonprofit Center of South Puget Sound (www.npcenter.org) – Well regarded by Work Group members; offers a "financial camp" focused on needed business skills
Toolkits
The Consumer-Operated Services Program (COSP) Multisite Research Initiative is a federally-funded national effort to discover to what extent consumer-operated programs are effective as an adjunct to traditional mental health services in improving the outcomes of people with serious mental illness. One product from that research is the COSP Evidence-based Practice KIT ("Knowledge Informing Transformation"), which is under development and to which Washington State has served as a review state.[12] When complete it will provide important content for the provision of technical assistance to consumer and family run organizations in Washington State.

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[12] Centers for Mental Health Services (November, 2007). <u>Consumer Operated Services (COSP) Evidence-Based Practices KIT – Field Review Draft</u>. Unpublished manuscript. Rockville, MD: Substance Abuse and Mental Health Services Administration.