

Integrated Healthcare System for Persons with Serious Mental Illnesses

Summary of Input from Peers and Family Members

Background Information

In August 2011, the Arizona Health Care Cost Containment System (AHCCCS) and the Arizona Department of Health Services/Division of Behavioral Health Services (ADHS/DBHS) convened a Peer and Family Engagement Work Group to design and implement a process for obtaining input from persons with Serious Mental Illnesses (SMI) and their family members regarding the integration of physical healthcare and behavioral healthcare services (*see <http://www.azdhs.gov/diro/integrated/index.htm> for more details and the latest information about this planned effort*). Work Group members included representatives of peer-run and family-run organizations, AHCCCS, ADHS/DBHS, and St. Luke's Health Initiatives (SLHI).

The Peer and Family Engagement Work Group used Community Based Participatory research, an evidenced based approach used in public health to engage communities that share an issue or concern; and then adopted the use of focus groups as the means to gather the collective opinion of persons with SMI and their families. As a result, the Peer and Family Engagement Work Group asked each peer-run and each family-run organization in Maricopa County to host a focus group and each did so. Six focus groups were conducted at the following organizations: Family Involvement Center (9/22/11), CHEEERS (9/23/11), REN (9/26/11), MIKID (9/28/11), Visions of Hope (9/29/11), STAR West (10/13/11); a seventh was held for the four Maricopa County NAMI-affiliates at the Disability Empowerment Center (10/17/11). Additionally, SLHI conducted nine individual interviews with additional respondents in order to reach some who were not affiliated with these organizations. Questions/topics were developed by the Peer and Family Engagement Work Group and finalized by DBHS. The same questions were used for the focus groups and interviews, although the interviews were tailored to each individual's circumstances. Focus groups were facilitated and documented by individuals with prior training and experience facilitating meetings with peers and families. SLHI helped facilitate the input process and summarized the findings. This document was prepared for publishing by ADHS/DBHS and reviewed by the Peer and Family Engagement Work Group.

Participants

Over 100 people attended some or all of a focus group. Participants were primarily persons receiving services in the public behavioral health system or family members of those receiving services. There were some service providers in the focus group held for the NAMI affiliates—input collected was analyzed recognizing this exception.

Findings and Observations

This report summarizes comments shared in the focus groups and interviews. Where similar comments were made in multiple settings, this is noted; however, the process was not designed to lead to consensus recommendations. Statements in this document reflect the opinion of participants and are not the author's words.

There were some pervasive themes that threaded through the focus groups and interviews. **Peers and family members want a system in which:**

- The administration and providers really LISTEN to them.
- They have VOICE in planning, implementing, and evaluating their own healthcare.
- They are treated with RESPECT and not stigmatized for having a mental illness in either the behavioral health or the physical health aspects of the system.
- Each person is treated as unique and healthcare is INDIVIDUALIZED accordingly.
- Providers are HIGHLY SKILLED in serving persons with Serious Mental Illnesses.
- Services are coordinated, consistent, and of high QUALITY.
- The focus is on improving health OUTCOMES and ensuring health EQUITY.

Impressions about an Integrated Healthcare System

With few exceptions, participants liked the concept of an integrated healthcare system as long as there would continue to be a choice of quality providers and the ability to change providers. Participants noted that **an integrated healthcare system offered potential for the following:**

- Coordination of medications. This was a common concern among participants because of the potential for medication interactions and adverse side effects. Many felt it would be beneficial if the prescribing providers were well aware of all the medications that the individual was taking and of all the individual's health conditions and health issues.
- More holistic approach to healthcare. Many spoke about the importance of being treated as a whole person and of various providers looking at the interaction of the mental, emotional, and physical aspects of health.
- Better communication among all team members. While some noted that an integrated system is no guarantee of better communication among all team members, it does offer the potential via shared health records and perhaps via co-location of some services.
- Greater accountability for healthcare delivery and health outcomes. Some noted that the leadership of the health plan sets the tone for the whole organization. If the contract requires accountability for both service delivery and for health outcomes, this could lead to improvement at all levels of the organization.

Participants also expressed the following **concerns for consideration in the design of integrated healthcare:**

- Confidentiality. While there are advantages to having both behavioral health and physical health providers in the same health plan, some were concerned that their medical records might be shared beyond a need to know. Some stated that they did not want all their providers to know everything about them for varying reasons.
- Loss of current providers. Perhaps the most commonly mentioned concern was the potential for having to change primary care doctor and/or specialists. Several participants commented that it had not been easy for them to find a primary care physician or specialists with whom they could work well and feel comfortable. If they could keep the same doctors, they would support integration of systems, but they would not support it if it meant losing their chosen providers.
- Choice of providers. Concern was expressed about having fewer choices of doctors and reduced quality of providers among those contracting with the integrated health plan.
- Access to specialists. There were many questions about how referrals to and delivery of services from specialists would work.
- Service array. Some participants expressed concern about losing some of the services they currently receive and really need.
- Formularies. Some participants expressed concern about losing coverage for specific medications that they are taking at this time.
- Wait time. Although primarily related to co-located services, several participants expressed concern about integration resulting in a longer wait time to see the doctor, either the primary care doctor or the psychiatrist.
- Decision making/authorizations. There were questions about who had the final say in an integrated healthcare system and whether the primary care doctor would serve as a gatekeeper for behavioral health services, as well as other medical specialty services, or vice versa.
- Changes to the current behavioral health service delivery model. There were questions about whether the current service delivery model would change, e.g., clinics, peer-run organizations.
- Communication and coordination. There were concerns about mechanisms that would be put into place to ensure communication and coordination of service delivery among providers in the integrated healthcare system. It was noted that being on one health plan or even in one location would not be sufficient to ensure communication and coordination.
- Stigma. Some were concerned that the creation of a "Specialty RBHA" would serve to further stigmatize persons with SMI. One person noted that this should not be a carve-out, but rather a fully integrated health plan.

A small number of participants expressed support for greater integration of service planning and delivery, but not necessarily under a single health plan.

Integration with Medicare

There were mixed opinions on the value of integrating a person's Medicare plan with the integrated behavioral/physical health plan. On the positive side, it was noted that full integration would facilitate billing and be less confusing. Some commented that they already had their Medicare and Medicaid services through the same health plan and that this worked well for them. Concerns focused primarily on fear of losing services and increased out-of-pocket costs.

Co-location of Services

There were mixed opinions about the co-location of primary care and behavioral health services. Some seemed to like the idea very much for the following reasons:

- Ease of access. This would reduce the need for transportation and make it convenient to see the primary care doctor. This might be particularly beneficial to seniors or those with mobility challenges. It could result in getting in to see the primary care doctor sooner.
- Better coordination, possibly leading to improved healthcare. If the doctors were in the same place, it might be easier for them to review an individual's healthcare plan, status, medications, etc. and might be conducive to more integrated healthcare.
- Improved likelihood of getting care. Some noted that it is sometimes difficult to encourage their family member to go to the doctor. Having a primary care doctor at the clinic might increase the probability that the person would see the doctor.

Some were opposed to co-location; others who were not categorically opposed still had concerns. The concerns included the following:

- Space. It was noted that it would be hard to incorporate primary care services into existing clinic locations.
- Scale. Some participants were concerned about the clinic taking on a warehouse appearance and feeling. One person asked if this would be like going to the Veterans' Hospital. Some commented that this could be addressed by providing services on different floors of an office building and having different entrances for different purposes.
- Contagion. Some participants were concerned about people with contagious medical conditions being in the behavioral health clinic with those whose immunity might be compromised.
- Length of wait time. There was some concern that people would have to wait a long time to see the primary care doctor if he/she were located in the clinic.
- Lack of choice. Some expressed concern that the individual would not have a choice and would need to be seen by the primary care doctor who was working that day. Concern was expressed about the quality of care if the primary care doctors were full time at the clinic and saw no one other than individuals in the behavioral health system.
- Stigma. Once again the issue of stigma was mentioned and concern expressed about being relegated to one location where only persons with SMI would be served.

Choice

When asked if it would be important to have a choice of integrated health plans, most indicated that they would prefer a choice, although a few said that it did not matter much to them. Advantages of having a choice of integrated health plans were greater competition for members and more accountability to members, hopefully leading to better healthcare.

Participants felt that there absolutely had to be a choice of doctors, both psychiatrists and primary care doctors, and that everyone needed to have the information required to make an informed choice of providers, whether or not they had a choice of plans. At least one respondent indicated that an important choice for him/her would be whether to see the primary care doctor at the clinic or in the doctor's private office.

Another issue related to choice that came up in several focus groups and interviews was the choice of whether to opt-in or opt-out of the integrated health plan. Some indicated that they would be willing to consider getting their behavioral/physical healthcare from the same health plan, but wanted the option of deciding to continue with the arrangement they currently have if they were not satisfied with the choice of providers in the integrated health plan.

Concerns about not having a choice included the following:

- **Formularies.** Some choose their health plan based largely on whether the medications they take on an ongoing basis are included in the formulary and not all health plans are the same in this regard.
- **Consistency and quality.** Participants were very concerned about the consistency and quality of care, particularly if they have chronic medical conditions. Keeping a doctor or other provider that is a good fit for the individual is a major concern. Several participants indicated that they would choose the health plan that includes their primary care doctor and/or specialists.
- **Coercion.** A few participants expressed concern about being forced to see a primary care doctor if they did not want to do so or being dropped from behavioral health services for non-compliance with the primary care doctor's orders.
- **Resources.** A concern was raised about the adequacy of resources to make a choice of plans a reality.

Enrollment of AHCCCS-Eligible Family Members in the Same Integrated Health Plan

Opinions on whether to include AHCCCS-eligible family members were mixed. Some thought it would be easier for families if they could all be enrolled in the same health plan as long as there was a choice of health plans. Some plans, it was noted, might be more child or family-friendly than others. **Other than family convenience, advantages might include:**

- Better recordkeeping and better familiarity with the whole family, which would facilitate taking the health of the whole family into consideration in the treatment of any one member.
- Early detection of genetic predispositions and initiation of prevention services.

Several participants had no dependents or other family members who were AHCCCS-eligible or enrolled. While several of them thought the idea was promising, they had no direct experiences and, therefore, no strong opinions on the subject.

A few were opposed to the concept and their reasons varied. Others were not necessarily opposed to coverage for families, but simply did not want their children coming to the behavioral health clinic to receive primary care services, if services were to be co-located.

Other concerns voiced include the following:

- **Appropriateness of providers.** If children were to be seen, the health plan would need an array of pediatricians and children's specialists.
- **Service array.** Some felt that it would not be feasible to provide the array of services needed for people throughout the lifespan.
- **Waiting time.** Some were concerned that seeing family members would lengthen the wait time to see the primary care doctor.
- **Costs.** Some inquired if covering families would increase or decrease costs.
- **Care coordination.** There were concerns about how care to the family would be coordinated.
- **Choice.** There were concerns that the whole family might be required to see the same primary care doctor.

Care Coordination

The questions posed focused on coordination of care rather than case management. However, in some cases the two concepts were blurred in the responses; this must be taken into consideration when reading the comments below.

Several participants said there should be a neutral party charged with care coordination; that is, someone who does not “work for” either the psychiatrist or the primary care doctor. Several said that care coordination should be a responsibility of the case manager or case worker (distinctions were not made between these two titles). One participant said the care coordinator should not have more influence than the clinicians on the team. Others who might serve as the care coordinator mentioned by one or more participants included the following: a peer, the primary care physician, the psychiatrist, a social worker, a nurse, the site manager, and a medicine man. Some commented that care coordination should not be the responsibility of the primary care doctor due to concerns about behavioral health needs being overshadowed by other health needs. They felt that behavioral health should “drive” the process. Several participants expressed that there should be no care coordinator and that this should be done by the person him/herself or the family, if possible. A few participants commented that the care coordinator should be whoever relates best to the individual and that this would vary from person to person. Another commented that care coordination should be shared among the team members.

It was noted that whoever is charged with care coordination functions needs to have knowledge of Serious Mental Illnesses, experience working with persons with Serious Mental Illnesses, a thorough understanding of behavioral health related medications and their side effects, and familiarity with the physical healthcare system as well as the behavioral healthcare system. The care coordinator needs to listen to the person for whom they are coordinating care and know the person well enough to support their active participation in their own healthcare. The care coordinator should have at least a bachelor’s degree, receive ongoing training, and have regular performance reviews. Functions of the care coordinator should include ensuring that all providers involved with the person provide timely information in a format that is understandable to the person and all other team members and supporting the person in navigating all aspects of the healthcare system.

Several commented on the need for a reasonable caseload for case managers and/or care coordinators. The importance of “customer service” was highlighted by many.

Other concerns about care coordination included: how to ensure participation of some persons with Serious Mental Illnesses who may be at times be unable to make their needs known verbally, how to avoid requiring the individual to tell the same story repeatedly, how family voice can be included, how to ensure that doctors share information, and how to ensure communication among team members in general. These are issues that participants would like to see addressed in the care coordination process.

Service Planning

When asked about their Individual Service Plan (ISP) and desirability of a broader “recovery and wellness” plan, participants had many comments. Most participants who commented on this subject stated that behavioral health and physical health issues should both be addressed in the plan, whatever it is called.

Participants would like the plan to be:

- Written with their input.
- Correctly reflect their current situation and goals (goals should be real).
- Implemented in collaboration with their case manager and all team members.
- Updated regularly to reflect their changing situation and goals.

It was noted that the plan could have particular value at times of transition, e.g., from school to work, from one type of living situation to another, from the children’s healthcare system to the adult healthcare system. The importance of

focusing the plan on the person's strengths was underscored by some as was the need for individualization and creativity. Participants would like to be provided a copy of the plan.

The Team

Most who commented on the composition of the team in an integrated system stated that it should include the current team members plus the primary care doctor, specifically the individual him/herself, case manager, psychiatrist, nurse, counselors, rehab specialist, and recreation specialists. There was much support for the inclusion of a peer support specialist and a family support specialist. As one participant put it, "The team should include all who care about and are involved in supporting the person." Some family members felt it was important for them to be on their family member's team, too. At least one person commented that there should be a pharmacist on the team and another noted the important role of the team in medication monitoring. It was noted that the team should take an active role in the implementation of the plan.

Role of the Peer Support Specialist and Family Support Specialist in the Team

The importance of peer and family support specialists was underscored in the focus groups and interviews. It was noted that peers can help instill hope in the person whom they are supporting. One of the peer support specialists who attended a focus group stated that she received hope from the peer who supported her and that she held that hope until she could then share it with another. Others echoed this in their own words, noting benefits ranging from reducing isolation to helping avoid hospitalization.

From the participants' perspective, the **keys to success are**: having a peer support specialist from the beginning; good matches; quality peer support; low turnover; having consistency in support; having the peer support specialist available as-needed; and having the peer support specialist checking in on regular basis.

When asked about the **roles of peer support specialists**, the following were mentioned: mentor, advocate, role model, "living proof," go-to person, educator, coach, and system navigator. The peer support specialists:

- Listen and share their own stories.
- Support the empowerment of the individual so that he/she can become a better self-advocate.
- Help the individual to communicate.
- Help the individual to prioritize goals.
- Provide information about community resources that may not be known to other team members, the pluses and minuses of the resources, and how to access them.
- Could provide broader peer support to the individual, if they have other physical health issues themselves.
- Could provide professional development to newer clinicians who may have limited experience working with persons with Serious Mental Illnesses.

Several stated that peer support should be written into all plans.

Peer support specialists working in an integrated healthcare system will need:

- Initial and ongoing training and education. Particularly, to support the individual in all aspects of the plan (or ISP), they will need training related to the physical healthcare system.
- Effective supervision and performance reviews.

An environment where confidentiality is respected and boundaries upheld.

While no one rejected the idea of having peer support specialists in an integrated system, there were questions about how this would work and how the peer support specialist would work with the case manager, care coordinator, or both if they were not the same person. It was noted that primary care doctors and other providers in the physical healthcare system would likely need information and training about peer support—how it works and its value.

There was also interest in having family support specialists available. **Family support specialists:**

- Should be family members and should be part of the team.

- Can be instrumental in helping families get through tough times.
- Help families deal with the stigma that is attached to mental illness.
- Offer confidentially for the family to discuss things they don't feel comfortable talking to others about.

The availability of peer and family support specialists should be publicized so that these services are better understood and used often in the integrated healthcare system.

Wellness, Prevention, and Chronic Disease Management Services

Among those who commented on the subject, there was widespread support for including services to promote wellness, prevention, and chronic disease management in an integrated healthcare system. **The types of wellness, prevention, and chronic disease management programs and services that some would like to see in an integrated healthcare system include the following:**

- Diabetes counseling
- Cooking classes and other nutrition programs
- Weight management programs
- Physical activity (including workout rooms, equipment, and gym memberships)
- Skin care (medication related conditions), smoking cessation programs
- Pain management
- Stress management
- Life skills classes
- Massage
- Acupuncture
- Tai Chi and yoga
- Reminder calls
- Home health checks

The importance of programs and services focused on co-occurring conditions was also noted (including Alcoholics Anonymous and Narcotics Anonymous), as was the importance to health of outings, recreation, and socialization.

Other services suggested include counseling, dental, flu shots, housing, mobile health screening (such as mammograms and HIV screening), peer support, prenatal care, respite, support groups, transportation, vision, and well-woman exams. The importance of educating those receiving services about behavioral health, diagnoses, medications, etc. was highlighted, as was the importance of having time for discussion of these and other issues with one's primary care doctor and psychiatrist.

The importance of taking a holistic approach to health was highlighted, as was the importance of individualization. It was noted that activities need to be adult-oriented and designed to reduce rather than heighten stigma. Food served in clinics and other programs should be healthy and appealing, in order to reinforce the health messages. In the integrated system, there should be opportunities for lifelong learning about health and chronic disease management. There should be an emphasis on self-management of chronic diseases and peer support to assist with this (assuming peer support specialists have the requisite training on the subject). Furthermore, there should be recognition that behavioral health conditions and medications taken to address them may contribute to problems such as overweight, poor oral health, lack of physical activity, and such. Special attention and supports should be available to help counteract these factors. Several commented that peer and family support is an important tool in the promotion of wellness. **The only concern noted was the potential cost of offering an array of wellness, prevention, and chronic disease management programs.**

Technology

When asked about the use of technology for purposes ranging from electronic health records to personal health management, **some benefits identified included:**

- Medication monitoring and management (biggest one).
- Improved access to an individual's health information by various team members, including the individual him/herself, the primary care doctor, the psychiatrist, and other specialists (individuals also expressed desire to be able to enter notes in their own health records.)
- Convenience. One family member who was interviewed spoke of the benefit of her son being able to locate and make an appointment on-line for his blood draw with a lab near his home, which was far more convenient for him than the prior process had been.
- Ease and speed of communications. While acknowledging that access does not ensure communication, it was noted that this would at least facilitate communication. One participant noted that it would be beneficial if it were possible to communicate via email with the behavioral health clinics.

Concerns included:

- Accuracy of electronic information, confidentiality (including who has access to what data), data security, back-up systems, and data recovery plans.
- Lack of internet access. Some/perhaps many individuals with SMI do not have access to computers in order to access on-line information, educational materials, or health management resources.
- Need for training both on how to access on-line resources and how to understand information in the health records.
- Technology doesn't always work as planned.
- Technology should not replace human interaction.

Other Considerations Related to an Integrated Healthcare System

Other issues that surfaced during the focus groups and in the interviews included the following:

- Serving people who are diverse in language and culture. The importance of being able to serve persons whose primary or only language is other than English was noted by several participants, as was the importance of understanding the impact of culture on health and healthcare.
- Providing clear and simple information about eligibility, costs, etc. There were questions about whether there would be any changes in eligibility in an integrated healthcare system, as well as questions about out-of-pocket costs.
- Engaging a competent and sufficient workforce. Concern was expressed about having a sufficient pool of high quality providers, particularly primary care doctors, who understand behavioral health. The issue of turnover in psychiatrists was mentioned by participants and there was concern that there might be similar turnover in primary care physicians, which is not typically experienced in the physical healthcare system. Participants also spoke about the creation of new employment opportunities in an integrated system. They underscored the importance of requiring or at least making available training for those who would be working within an integrated system. The issue of compensation was mentioned, noting the importance of paying well enough that high quality providers are attracted to and stay in the system.
- Licensing. Questions were raised in one focus group about the impact of behavioral health licensing standards on an integrated healthcare system.
- Coordinating with other non-health related programs. There were questions from a few participants about the Freedom to Work Program and how this might be impacted by integrating the healthcare system.
- Surviving budget cuts. Concern was expressed about the impact of any future budget cuts, with at least one mention of fear that it would be easier to cut an integrated system than each of two separate systems.
- Ongoing involvement of persons with Serious Mental Illnesses and their families in planning, implementing, and evaluating the healthcare system. There was support from many participants for continuing to seek out and engage those who are impacted by services in the process of designing, developing, implementing, and evaluating the new system.

- Serving persons who are not designated as having Serious Mental Illnesses and a non-Title XIX population. Concern was expressed about persons who are in the “General Mental Health” population, as it was noted that there are individuals in this population whose needs are similar to persons designated as having with Serious Mental Illnesses. Concern was also raised about those how are not Title XIX eligible. There were also questions about how changes in the adult system will impact the children’s behavioral health system and the transition between the two.

Additional Focus Groups

On November 18, 2011, an additional focus group was held primarily for persons of African American descent. There were 22 participants, the vast majority unfamiliar with the public Behavioral Health system or mental illness in general (3 -5 participants may have been members/family members based on their knowledge and answers, there was no way to tell with certainty without explicitly asking the person to self disclose). While responses collected did not provide new information, the desire to have an advocate role in the system was expressed several times (i.e., each person in the system should be assigned an advocate).

On December 13, 2011, an additional focus group was held primarily for persons of Hispanic/Latino descent. There were at least 4 confirmed member/family member participants out of 8 total participants. Participants in this group expressed support for the health home concept and having their healthcare services through one health plan. They liked the idea that family/dependents get their healthcare through the same health plan as the person with SMI. They suggested that social workers get the role of care coordinators. They desire to have peer support specialists play a role in the new plan or system and they support the use of technology (i.e., would like to access their own health information online).

Attachment 1
Focus Group Questions

Q1: First, thank you to those who put themselves out there in doing the video. What caught your attention in the video? What did you like or not like about the idea of getting all your health care through the same health plan?

Q2: If a single health plan is created to oversee all your health and behavioral health services, you may no longer have a choice of health plans, even though you would still have a choice of doctors. Do you have any concerns about that? If so, what are they?

Q3: Many individuals with Serious Mental Illnesses have dependents or family members who are also on AHCCCS. Would it be helpful if dependents or family members could be enrolled in the same AHCCCS health plan as you (...or their family member who has a Serious Mental Illness)?

Q4: A health home is an approach or way to give integrated care that means that, besides having the same health plan for your psychiatrist and your primary care doctor, all the team members in your recovery plan have to work together. Who should be responsible for coordinating all the team members? Where should the coordination of services take place?

Q5: If you have Medicare coverage, would you prefer to get all your services, including those covered by Medicare, from the same health plan?

Q6: Can you describe how an ISP helps you to meet your recovery and wellness program?

Q7: In the Raise Your Voice focus groups, it was noted that peer support services are important to you because peers are uniquely qualified to listen, help, and offer hope to one another. What role should the peer support specialist or family support specialist have in your recovery plan?

Q8: Many individuals with Serious Mental Illnesses die 25 years younger than the rest of the population. An integrated health care delivery approach may help people with Serious Mental Illnesses live longer. Keeping that in mind, what types of wellness, prevention, and other services would you like to see provided to promote recovery, help you stay healthy, and help you manage your illness or health problems?

Q9 Today, technology is being used to support wellness, treatment, and care coordination in health care—from electronic health records, to web-based patient education, to tracking your health on-line. Does using technology in these ways appeal to you? What concerns do you have?

Q 10: Is there anything else you would like to add?