

**Developing the Office of Individual
and Family Affairs (OIFA) in Arizona**

November 15-16, 2007, Phoenix, AZ

**Report from:
The Depression and Bipolar Support Alliance (DBSA) to
The Arizona Department of Health Services/
Division of Behavioral Health Services (ADHS/DBHS)**

**Report on Developing The
Office of Individual and Family Affairs in Arizona**

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Acknowledgments

The consulting team wishes to express gratitude for the efforts of those who contributed to the development of this report. Many individuals contributed their time, expertise, and commitment to producing this important document, making it possible to ensure multiple perspectives from individuals, family members and State employees throughout the system. Thanks also go to Eddy Broadway, Deputy Director of the ADHS/DBHS, whose foresight and commitment to the welfare of mental health consumers made this event possible.

Special thanks are also due to those who participated in the Individual and Family Voice Summit held on November 16, 2007 (see List of Participants, page 11), and especially to Tom Kelly, the new Director of the Office of Individual and Family Affairs. His unwavering dedication and strength made this important event exceptionally successful.

The consulting team would also like to express thanks to the Substance Abuse and Mental Health Services Administration's Center for Mental Health Services, whose funding made this project possible.

Finally, thanks go to the National Association of State Mental Health Program Directors (NASMHPD), National Technical Assistance Center (NTAC) for their financial support, and to staff member Tim Tunner, who helped with this project, and with the production of this report.

Introduction

The Arizona Department of Health Services, Division of Behavioral Health Services recently created an Office of Individual and Family Affairs (OIFA) as part of their Strategic Plan to assure that the voices of individuals receiving services and their family members be heard in the state of Arizona. This demonstrates significant insight by the Office, and particularly by the Deputy Director, Mr. Eddy Broadway, into the mental health recovery process. Working to ensure the strength and effectiveness of this new Office, the State also enlisted the assistance of outside consultants to work with the ADHS/DBHS, the newly hired Director of the OIFA, and the already-established consumer and family “leadership” that exists in Arizona. Larry Fricks of the Depression Bipolar Support Alliance (DBSA) and the Appalachian Consulting Group, and Peter Ashenden, Executive Vice President of DBSA were therefore contacted to assist in this important process.

The consulting team’s first day involved a focused discussion with ADHS/DBHS Senior Leadership Team members to understand their anticipated and desired outcomes in establishing the OIFA. The next step was to meet with the Director of the OIFA, and discuss his perceptions of his role, both within the ADHS/DBHS, and in his work with the constituents that he will be serving in the state of Arizona. The second day of the consultation was used to hold a Consumer and Family Summit with approximately 25 consumer and family leaders/advocates. Assisted by the consultants, the Director of the OIFA held a focused discussion regarding what these representatives would like to see as the purpose of and outcomes from this new Office of Individual and Family Affairs.

The following recommendations are findings and observations based on feedback received from each group over the two day consultation. Following the recommendations are notes taken from the two days’ meetings. Many of the actual statements made by individuals who played an important role in this process are retained.

The consulting team would like to thank the ADHS/DBHS for their insights, and for sharing their thoughts on the inner functioning of the department. The consultants also want to thank the Director of the OIFA for his ongoing support, insights, and perspectives. Finally it is critical to mention the group of consumer and family leaders who were willing to participate in this important event. As noted during the event, the consultants would like to reiterate their availability for any follow up assistance that may be needed as the Office of Individual and Family Affairs continues to grow and develop its roles in the State of Arizona.

Recommendations

The following recommendations are based on the discussions and observations over the course of the two day consultation:

1. The Director of the Office of Individual and Family Affairs (OIFA), to be optimally effective in his or her role, will need to be able to report directly to the Deputy Director/Commissioner of the ADHS/DBHS. Furthermore, he/she will need to be a member of the Senior Leadership Team that oversees all operations of the Division of Behavioral Health Services.
2. Regularly established meetings/teleconferences of the OIFA Director, consumer/family organization leaders, and people using mental health services in the state of AZ must occur, preferably on a quarterly basis. These meetings should be coordinated from the OIFA. This will help create an environment where information flows from those using the services and their representatives to the State administrators, as well as from the administrators to those using the services and their representatives. It is also important for this group to have an active role in the development and execution of transformation, recovery focused, and person-centered services that will be offered by the Department of Mental Health.
3. Skill building and knowledge exchange activities should be established by, and based from the Office of Individual and Family Affairs, with the purpose of serving consumer/family organization leadership, and those using mental health services in the state. This should be in the form of an annual or semi-annual conference or other mutually agreed upon fashion that will assure continuation of these important activities.
4. The OIFA Director should visit each consumer operated program in the state twice annually to establish an important contact/support role with each of the agencies. This will facilitate a healthy dialogue, and allow the Director first-hand experience of the services and programs being offered to participants.
5. There should be a regular mechanism for communication between the OIFA and each funded government agency that participates in the delivery of mental health services in the state. This action will have to be initiated and followed through by the Director of the Division of Behavioral Health Services to assure implementation. The reason for this open communication is to ensure that all parties are working together for the common good of the people receiving services. These agencies include, but are not limited to, Vocational Services, the Department of Health, the office that oversees all welfare and entitlement programs, the Office of Substance Abuse Services.

6. There should be continuing education, training, and skill building of Consumer Peer Specialists in the state. The Office of Individual and Family Affairs should have a significant role, if not oversight responsibility, for the development and provision of these services.
7. A Statewide Advisory Board should be created to support and provide suggestions to the OIFA. This board should be comprised of consumer and family representatives/advocates such as those who participated in the second day of this consultation. The board should meet at least bi-annually in person, and quarterly via teleconference or videoconference. The bi-annual meetings could be arranged to coincide with other recommended conferences.

Final comments: The consultants feel that ADHS/DBHS has the right person (Tom Kelly) in heading this important office, and that he clearly has the vision and skills needed to be a successful Director, not only in his position, but as a representative and promoter of the voice of people receiving services in the state. Ongoing support from and access to the ADHS/DBHS, will be a major factor in his success. Based on observations from the visit, it seemed clear that his success, and the success of the Office of Individual and Family Affairs, is the goal of the ADHS/DBHS leadership.

Respectfully Submitted,

Larry Fricks
Peter C. Ashenden

DAY ONE ACTIVITIES 11/15/07

The following are notes from the two-day meeting. Efforts were made to maintain individuals' own words as much as possible.

Morning Meeting 10:00AM – 11:30AM Room 200B

Introductions

The OIFA Director introduced the DBSA and NTAC Technical Assistance (TA) Team to the Senior Management Team members. Each person from the TA Team shared a little about their work experiences, and what they hoped could be accomplished over the next two days. Each member from the Senior Management Team present shared some of their hopes for the next couple of days.

DBSA and NASMHPD TA Team

Peter Ashenden - Executive Vice President – DBSA
Larry Fricks - Vice President for Peer Services – DBSA
Tim Tunner - Project Coordinator – NASMHPD/NTAC

ADHS/DBHS Senior Leadership

Eddy Broadway - Deputy Director, Arizona Department of Health Services
Laura Nelson M.D. - Chief Medical Officer
Ann Froio - Health Operations and Systems Administrator
Brenda Thomas - Senior Projects and Policy Advisor
Dr. Wayne F. Goulet - Director of Operations for Clinical and Recovery Services

Arizona Overview

The Deputy Director of the ADHS/DBHS opened discussion by providing the TA Team with an overview of some current issues in the behavioral health system in Arizona. He mentioned that Arizona had “consumer and family voices” throughout the system, but that they appeared to be somewhat fragmented in the adult system. Representatives in the children’s system of care appear able to work together much better than some of the adult system representatives. One of the Deputy Director’s hopes from this consultation was that the Office of Individual and Family Affairs could help bring together the fragmented voices in the adult system.

General Discussion

A discussion ensued following the Deputy Director's overview. The group raises several issues and concerns, and discussed ways to address them.

One concern raised was that "Consumers can't seem to get together." The TA Team mentioned that one way to help bring them together, besides the establishment of an Office of Individual and Family Affairs, is an annual conference where consumers and family members could voice and prioritize their issues and concerns with the system. Throughout the country, employment, housing, and transportation continue to rank high on priority lists of consumer and family groups.

The consultants made another suggestion that could help bring consumer and family voices together; an Advisory Board established for the OIFA. This Board could work to create a sense of urgency or a "let's get stuff done" attitude, that could be a conscious effort to get the different representatives to work together. The consulting team mentioned that in order to create most of these noted recommendations it is "imperative that you fund these efforts or else they will die."

It was noted by some participants that some individuals (providers and consumers) in the system do not appear to be on board with, and may even end up working against a "vision of recovery and person-centered planning principles." One response to "How do you mobilize the grassroots folks to help combat some of this antiquated-type thinking?" included hosting conferences and town hall meetings around the state. In such settings people could be surveyed to understand what people receiving services in the different communities want in their lives. This would provide a vision of what recovery could mean for consumers served by the system.

One of the consultants stated that, "In order to move to a more 'consumer and family friendly' culture it is necessary to bring a united voice to the table and that the voice move in one direction!" Bringing a united voice to the table may help change people's attitudes and beliefs about people with behavioral health issues, along with their "wants and desires."

Specific Group Recommendations

A question was asked of meeting participants, with the following responses: "What could be some things that an Office of Individual and Family Affairs initiates and implements in order to help include the voice of the individual and family across the system?"

1. Create "Arizona Circles" - This could be a forum for dialogues between community members throughout the state

2. Create a Consumer Advisory Council to the OIFA - This is a very important component for the functioning of an OIFA, which is heard repeatedly in other states
3. Statewide Infrastructure - There should be a statewide infrastructure developed to support consumer representation through the OIFA to the State, and to regions within the state
4. Tap into SAMHSA Networking Grants – These \$70,000 grants are made available as funding is appropriated from the federal government
5. Create a feeling of “altruism” in the state - This could will help people “move in the same direction” for the welfare of consumers (no recommendations were made for how to achieve this recommendation)
6. Tap into “lapse dollars” - Many departmental budgets have unspent money towards the end of the year (or budget or grant cycle) that the OIFA could tap into to help “pull some people together to get things done”
7. Technical Assistance - The OIFA should help provide TA to build necessary business operations for consumer and family run organizations. Available funding would need to be found

The TA Team stated that to accomplish such goals as mentioned above, the Office of Individual and Family Affairs would need funding for meetings, facilitators (people from outside the community) and regional and statewide conferences. The consultants recommended that the Office of Individual and Family Affairs should have access to funding from different grants, such as the Mental Health Block Grant, Substance Abuse Prevention and Treatment (SAPT) Grants, State Incentive Grants (SIG), and Substance Abuse Coordination (SAC) Grant funds. Another recommendation was to include this Office as part of the strategic planning for State grant applications. Finally, creating regular communication between the Office of Individual and Family Affairs and the State’s Behavioral Health Planning Council was another recommendation which could help accomplish the aforementioned goals.

The group also recommended that the Office of Individual and Family Affairs have a close working relationship with the Interagency Affairs Office to ensure that the voice of individuals, youth, and family members are heard across all systems. The OIFA needs to work with other similar offices in other State departments to ensure that both sides understand each other’s issues and challenges, and can work together to help people across the state.

The most important recommendation for the Office of Individual and Family Affairs was to have a “doable agenda,” with short term, intermediate, and longer-term goals. The TA Team will be working with the OIFA to develop a proposed action plan for the next few months.

The Deputy Director's and Senior Leadership Team's vision for AZ OIFA from the 11/15/07 morning meeting

(This synopsis is based on the Team's comments through the morning meeting).

The adult mental health advocacy community will provide clear direction on key system transformation priorities to enhance strength-based recovery, and support the OIFA office to implement statewide inclusion from consumers and families to determine key recovery priorities.

Action Plan

The following are specific actions the group recommended based on conversations from the morning meeting:

1. By March 30, 2008 the OIFA Director should visit all consumer operated service programs (COSP) to seek members for an Advisory Council for the Office
2. Advisory Council members should meet for one day twice annually to provide input to the OIFA. Meeting sites should be rotated around the state. Travel reimbursement, coffee, drinks, refreshments and lunch should be provided at council meetings, and a budget should be developed to support the costs. The first Advisory Council meeting should be held by April 30, 2008
3. At the first meeting, Advisory Council members should help plan a process using technology like the *Survey Monkey* to provide immediate input from consumers and family members on policy and other issues as needed
4. At the first meeting, Advisory Council members should help plan a Speakers Bureau to promote system transformation and reduce stigma
5. The OIFA should support a statewide consumer conference and/or regional conferences, with a key outcome being that the attendees vote on five top priorities that will help drive the work of the OIFA and system transformation
6. Prior to the start of the state legislature in January 2008, the OIFA Director should meet with mental health advocacy organizations, including Mental Health America (MHA), The National Alliance on Mental Illness (NAMI), and DBSA
7. By June 30, 2008 the OIFA should begin work on implementing statewide continuing education for Peer Specialists as required in CMHS guidelines released on August 15, 2007. The OIFA should facilitate the provision of ongoing continuing education for Peer Specialists, by using web-based technology, and by hosting quarterly meetings that are rotated around the state

DAY TWO ACTIVITIES 11/16/07

The following notes were taken by Eva Stoddern, scribe for the meeting. Efforts were made to maintain individuals' own words as much as possible.

The Individual and Family Voice Summit occurred from 10:00am-3:00pm in Phoenix, AZ at the Arizona Department of Health Services.

Individual and Family Voice Summit, State Representatives

Tom Kelly - Director of the Office of Individual and Family Affairs - Facilitator
Eva Stoddern - Clinical and Recovery Transcriber

Guest Speakers

Peter C. Ashenden - Executive Vice President - Depression and Bipolar Support Alliance (DBSA)
Larry Fricks - Vice President of Peer Services - DBSA and Director Appalachian Consulting Group, Inc.
Timothy P. Tunner - Technical Assistance Project Coordinator, National Association of State Mental Health Program Directors (NASMHPD)

List of Participants

Larry Belcher - Recovery & Resiliency Advisor - Cenpatico
Kathy Bashor - Director - PSA Art Awakenings
Trish Bleth - Director Consumer of Recovery Services, Magellan
Mona M. Casarez - Peer Coordinator, PSA
Wendy Cholfin - Manager of Children & Family, Magellan
Greg Dicharry - Peer & Family, Magellan
Kevin Ferris - C.H.E.E.E.R.S.
Jody Gardner - Program Coordinator, La Frontera Center
Cynthia Henry - Family Mentor, Magellan
Judi Holder - Recovery Services Administrator, Recovery Innovations
Vicki Johnson - Executive Director, MIKID
Jon Joshevama - Manager of Quality Utilization Review, Pascua Yaqui
Sara Scalzo Kaczmarzyk - Community Advocate, Cochise County
Jane Kallal - Executive Director, Family Involvement Center
Merv Lynch - DBHS
Regina Koch-Mart - CEO, HOPE Inc.
JoAnn Mendoza - Pascua Yaqui
Ellen Rose, BHPP - Marc Center East Village
Ron Schmidt - Deputy Director, HOPE Inc.
Ora Seymour - Apache Behavioral Health Services
Diane Taylor - Family Support, Cenpatico
Charlotte Webb - Peer Integration and Support Specialist, PSA

ADHS/DBHS Senior Leadership Guests:

Ann Froio - Health Operations and Systems Administrator

Brenda Thomas - Senior Projects and Policy Advisor

Dr. Wayne F. Goulet - Clinical Operations Director

Introduction and Welcome

The OIFA Director began the Summit by thanking Magellan for its sponsorship, and welcomed the consultants, Peter Ashenden, Larry Fricks and Tim Tunner, as well as the group of attendees who represented family members, individuals receiving services, Regional Behavioral Health Authorities (RBHA) and the Tribal Regional Behavioral Health Authorities (TRBHA) of the communities in Arizona. The OIFA Director shared the agenda, stating that the morning and early afternoon would include developing ideas, and then presenting them as group recommendations to the State administrators, including Eddy Broadway (Deputy Director), Dr. Laura Nelson (Chief Medical Director) Dr. Wayne Goulet (Clinical Operations Director), and other members of the DBHS Senior Management Team that would be joining or scheduled to attend later in the afternoon.

Introduction of the Technical Assistance Team

Each of the three guests took a moment to introduce themselves and give a brief overview of their background and the expertise they bring to the table.

Peter Ashenden

Mr. Ashenden is the Executive Vice President of the Depression and Bipolar Support Alliance (DBSA), which has its National Office in Chicago, Illinois. Mr. Ashenden stated that he is originally from New York City. While in New York, he had the opportunity of working with, “a dear friend and mentor,” Ed Knight, who started the Mental Health Empowerment Project. For the last 12 years, Peter was the Executive Director of the Mental Health Empowerment Project based in Albany, New York. The organization was founded on the belief that people tend to get well if they are able to participate in self help activities. DBSA also supports the belief that people are able to get better by participating in support groups. They have over a thousand support groups throughout the country, and they are also committed to providing mutual support activities at over 430 Chapters throughout the country. Mr. Ashenden further stated that he was honored to be invited to work on this project. Part of the expertise he brings is the development of a consumer network in New York, where people effectively communicate with each other and are moving forward in their lives. Mr. Ashenden thanked everyone for inviting him and for attending today’s summit.

Larry Fricks

Mr. Fricks introduced himself as currently serving as the Director of Appalachian Consulting Group, Inc., located in Georgia. Mr. Fricks stated that for 13 years, he served as the Director of the Georgia Office of Consumer Relations and Recovery, and before that he spent two years as the volunteer Executive Coordinator for the Georgia Mental Health Consumer Network, a statewide network that has around 3000 members. Mr. Fricks recently accepted a position with DBSA as Vice President of Peer Services. Mr. Fricks thanked everyone for being invited to Arizona, and stated that he is glad to be at the summit.

Tim Tunner

Mr. Tunner introduced himself stating that he is from the National Association of State Mental Health Program Directors based in Alexandria, Virginia. He stated that he is here as an observer, and to assist Peter Ashenden and Larry Fricks as needed. He also extended his assistance to Tom Kelly if needed, both during this two day consultation and in the future.

Introduction of Attendees

The Director of the OIFA asked everyone to introduce him or herself, and to share one thing that they expect from the Summit. The shared themes and expectations are listed below. Individuals' own words are maintained as much as possible:

1. "To help build a state-of-the-art Office for Consumer and Family Affairs"
2. Provide behavioral health education in public schools K-12
3. "Provide support for one another, not only in Maricopa County but around the state effectively"
4. "Develop sustainability, and build on the strengths we have"
5. Ensure that families from rural frontier areas have a voice
6. Make this office serve as a collaborator and unifier for consumer and family voices
7. Set a vision of policy and protocols for Peer and Family services.
8. Provide continuity and set a vision for policy and protocol for family services
9. "By the end of the day, I hope that this office will have a clear and polished foundation of protocols to build upon"
10. This office will hopefully diminish some of the misconception that is out in the communities about mental illness. The office should work to help eliminate the stigma of mental illness
11. Ensure assistance for those people who cannot help themselves
12. "Legitimize aspirations from consumers, and ensure they are not taken for granted"
13. Help those who are incarcerated get their voices heard

14. Provide the services needed to people released from correctional facilities into the community
15. “Come together as individuals to unite our strengths and to move systems in the directions we believe are the most helpful for us and the people we serve, and to build a strong collaborative.” The Office should help with such things as fund raising, grant writing, things “that most of us are always too busy trying to maintain. With this type of help, we can build the programs that are needed for the people we serve”
16. “Hope that we can all forget our differences so that we can come together and work to make the best mental health system possible. I believe that this is the only way that we can provide for the community”
17. “We as a community must recognize that there are many peers who are not at this table except thru advocacy. Advocacy is a major part of recovery, and we in the community need to mentor those people who are not here at this table, because we have a tremendous responsibility to the people to really look out for them and help them get well. I do not want to see them left behind”
18. Provide advocates to support people to help themselves
19. Create a series of meetings and forums for advocates to be able to capture the voices of the individuals and families who are not able to come to summits and meetings due to a lack of financial resources
20. “We should become a networking tool for recovery”

Video

After the introductions, a ten-minute emotionally stirring video was shown regarding the efforts of building a memorial in Washington D.C. This memorial will be for those who died while they were hospitalized in different State hospitals throughout the country. The memorial will be for people who lived and died in the hospitals, and were then forgotten. The memorial will be on two acres of land overlooking the Potomac River in Washington D.C. This DVD is part of a group effort to help these people be remembered as people and not as numbers. The video consisted of graves of people who died in the hospitals, and were buried in graves marked only with case numbers, and without names. A toolkit will be provided to those interested, including this powerful video that can be shown in schools and organizations to raise money for the project. By the end of this powerful video, there was general agreement by the group that everyone involved must not forget those who have come before them, and that the vision and work for developing the memorial needs to move forward.

What is an Office of Individual and Family Affairs?

Before breaking into a few small workgroups, members of the larger group shared a few thoughts and ideas with respect to how this office could be ‘envisioned.’

1. "As an avenue for the people we serve and their family members to have their voices heard throughout our delivery system"
2. "A focus for consumer and family participation with administrative assistance from the top"
3. "A high level voice that will be heard and listened to; not just a token voice"
4. "An avenue of statewide access for all consumers and family members"
5. "A diversity of voices from a broad spectrum of arenas"
6. "Representative of each RBHA and TRBHA"
7. "Everyone should be represented at the table"

Small Group Breakout

The group was asked to divide into small groups to provide ideas for how the OIFA can define its roles and responsibilities. The following suggestions were made to the larger group:

1. The Office needs more grassroots involvement
2. The Office needs good strategic planning
3. The Office should provide resources across the system
4. Opportunities and resources that do not require a budget should be sought out. The community should be brought together by encouraging collaboration between providers, advocates, family members, and services recipients
5. The Office should be inclusive of all voices, and should seek out representation from all voices
6. The Office should solicit and disseminate information between all providers and individual voices (formal and informal) to ensure continuity of care and shared voices
7. The Office should harness energy to spread across to other agencies. It should build respect and credibility through representation as a high level voice in the DBHS administration
8. The Office should work to establish protocols for those working in the field that do not have college degrees, yet bring the "lived experience" to the table. Also the inequity of income for some peer and family positions with respect to other positions should be looked at
9. There should be more integration with the adult health care system. There is a lack of navigation between DBHS and the Arizona Department of Economic Security (DES). There should be interaction with other agencies and stakeholders
10. The Office needs to reach out to rural communities
11. DBHS should cover all of Arizona
12. The Office should act as a clearinghouse of resources
13. Consumers, youth and family members should be employed by this office, and the Office should report directly to the DBHS Deputy Director
14. There should be standardized guidance for organizations across the state

15. The office is in need of a budget to assist people in getting to Summits and meetings that they can not otherwise afford to get to
16. The Office should advocate for those communities that are lost in layers of bureaucracy, and which do not know the different agencies that provide services to resolve their problems
17. The Office should represent all of the Arizona Mental Health System, including people with serious mental illnesses, people with substance use challenges, people with general mental health conditions, children, family members, and with respect to both Title XIX and XXI populations
18. The Office should advocate for continuity of services across the state for family members, consumers, and staff that will be affected by the development of clinical guidance documents

Larger Group Discussion (Vision and Mission)

The group discussed a vision and mission for this Office based on some of the ideas from the smaller group presentations. Their thoughts about themes that could go into creating a vision or mission for the Office follow:

1. The Office should have meaningful representation of a broad spectrum of individuals' and families' needs, wants, and dreams
2. The Office should work at renewing hope towards wellness through networking, and through the strengthening of individuals and families around the state
3. "Beautiful words are wasted on paper without the follow through"
4. The voice of this Office should be heard across the state
5. The Office should bring communities together for collaboration through providers, advocates, and family services. To include "our voices" [the consumer] and promote oversight and mediation between all providers, including for profit and non-profit organizations, the Office will need to advocate formally and informally, and it will need to use individual voices to ensure continuity in care between these providers

Best Practice Presentation – Larry Fricks

Mr. Fricks gave a short presentation on what he believed to be an important "Best Practice" for an Office of Consumer Affairs. He started by noting that he was with the Office of Consumer Affairs for over 13 years in Georgia. He went on to say that he believed AZ chose the right directive that the OIFA Director request to report directly to the Deputy Director of ADHS/DBHS. Having direct communication with the Deputy Director changes everything. Mr. Fricks told the group that first of all, in a bureaucracy, speaking to the head of an organization sends messages not only to the public, but to the bureaucracy itself that one's voice is heard. Mr. Fricks stated that those in the room who feel that their relationship should be directly with the Deputy Director are exactly right. He went on to explain how the Office of Consumer Affairs was able to accomplish that in Georgia, and gave the group insight of how Georgia was successful. He

encouraged the group to not settle for a middle-management position, but to talk to the Deputy Director this afternoon, and recommend what this Office wants implemented.

A member of the group asked Mr. Fricks “What if Eddy says no?” His response was a recommendation that the group write a formal letter and list these suggestions noting that these emerged as a consensus from the group, “You have more power than you think you do. Power begins with your thoughts, and then goes forward with it. Because we are survivors, we have developed survivor skills. It is important to fight for what you believe in.”

“Grassroots” Networking – Peter Ashenden

Mr. Ashenden gave a presentation on how to make consumer and family organizations work together from a grassroots level. He talked about coming together on common causes. One of his common causes in the state of New York was to close down hospital beds. He stated that people can live very well in a community with the right supports.

Mr. Ashenden advised the group to look for issues to rally around. He suggested to “Move ahead and don’t eat your own. It is hurtful behavior and will not accomplish anything. It will diminish the movement, and the only response you will get is from the bureaucracy may be ‘we told you so!’ We told you they could not play nice in the sandbox, no matter how hard they try.” He also advised the group to focus on developing an Advisory Committee. A Statewide Advisory Committee is instrumental to developing the Office of Individual and Family Affairs, as is family involvement in this committee. It is also important that the Advisory Committee takes “the voice forward from people that are using the services.” They should “Go back to the grassroots. Be in constant contact with the people who are using the services, and find out what they want.” The OIFA should set up an Advisory Committee to bring this information forward in a collective voice. It is far more powerful than an individual voice.

There is a networking grant offered by SAMSHA called a *State Networking Grant*. The OIFA and its representatives should apply for that grant. It is for \$70,000, which is not a lot of money, but it can be turned into a lot more money. This could help bring the consumer and family leadership group together for a skill building activity and thought exchange, such as to discuss directions in which the group is moving, and other concerns. This activity could also be used to develop people’s voices.

We’re asking people to come to the table to speak. Promote people’s voices. One of the ways to do that is through regional networking support groups. That is where you get your voice back again. The beauty of the peer networking opportunities is that you have a bottom up, top down approach. We need to hear from the voices of people that

are using the services, but in addition to that, we need to know what's going on in the bureaucracy, what is the direction that they are moving in, and feed that information out to the grassroots so that we get their interpretation and their reaction to it.

Mr. Ashenden suggested doing a survey of people at a regional conference can be a very effective tool. People should be asked "What is it that you want from your service system?" A 'give-away' of a token gift could also be used to attract participants. When the survey is completed, the people would get a raffle ticket for a drawing. The value of doing a survey is that the voices of individuals who are using the services, and what they want from their system, get heard. With this survey information then, he stated that,

The other thing that you can do is set a legislative advocacy agenda, where you can walk into the politicians' offices and say 'I have a block of two thousand, three thousand, four thousand registered voters.' The doors will open and the politician will invite you in to talk. That is how we bring our voices forward. Our voices are a very critical voice. There is a National Consumer Organization opening that we can take our voices not only to the State, but also to Washington. DC.

Mr. Ashenden said he has faith that the group will succeed, and said that he and Mr. Fricks are "only a phone call away." He also stated that he wants to see Arizona do very well, and believes that it is an important movement. "You will have success. Reach out to us. We have scores of people that we can get you in contact with, get you the resources you need, and figure out how to do this. We stand behind your success. Thank you."

Best Practices in Arizona (Large Group Discussion)

The group did not have the anticipated time to discuss Best Practices in Arizona. While many different individuals from around the state are working with different "Best Practice" programs, this portion of the agenda was tabled.

The group did discuss difficulties in networking. One stated problem is that there is no general clearinghouse of information for the public. Participants noted that this creates difficulty getting information from and between two agencies, such as The Arizona Department of Economic Security (DES) and the Arizona Health Care Cost Containment System (AHCCCS). Agencies should give information to service recipients, and send it to other agencies that would provide for their needs, so that no one has to find their own resources and/or "fall through the cracks." The State needs to create a structured clearinghouse of information.

Arizona's Office of Individual and Family Affairs

(The ADHS/DBHS Senior Leadership joined the Summit to see how the meeting progressed, and to hear what participants had to say).

One purpose of the Summit was to provide recommendations to ADHS/DBHS Senior Management regarding the development of an OIFA strategic plan for the next three years. Eddy Broadway, Deputy Director and Dr. Laura Nelson, Chief Medical Officer, both of DBHS, were not able to attend the afternoon meeting. However, Mr. Broadway and Dr. Nelson asked Ms. Ann Froio and Ms. Brie Thomas to represent them. Dr. Wayne Goulet was able to attend the meeting.

The OIFA introduced the DBHS leaders to the group, and gave a brief overview of the morning meetings. Each person in the group also introduced themselves to the Senior Management staff. Each member of the Senior Management staff then shared their role within ADHS/DBHS with those at the meeting.

The Summit participants presented their plans and recommendations of what they wanted the Office of Individual and Family Affairs to include as priorities. Their first and most important recommendation is that the OIFA Director should be a senior management level position. A top level position would help this individual focus on issues that are important to consumers, without having this voice "get lost in the shuffle, but reach the highest rung on the ladder and make every RBHA accountable." In addition, having the OIFA Director in such a high-level position would give him or her "the power and leadership to say, 'are you doing what you said you would? Are you walking the line?'"

The OIFA Director asked Ms. Froio and Ms. Thomas what they will take back to the Senior Leadership Team. Ms. Froio stated that everything presented was very important, and no one issue is more important than the other. She also stated that she shares in the passion, drive and ambition of individuals in the room. Ms. Froio stated that she made copious notes and assured that recommendations would be seriously discussed. Ms. Thomas stated that she was excited and energized, and was fascinated to hear what was mentioned, and will bring the information to other senior leaders.

Individual Recommendations from the Group to Senior Management Team

The meeting was closed by asking Summit participants to share one recommendation that they would want Senior Management members to hear. Following are comments suggested by the group:

1. Offer technical assistance and help on the business-oriented concerns that consumer and family run organizations throughout the state experience
2. "We want to ensure that all populations served in Arizona are included in the Office of Individual and Family Affairs"

3. The OIFA Director should report directly to the Director of Behavioral Health Services
4. Guidelines should be standardized for peer and family support
5. The OIFA should have a, "High level voice"
6. There should be statewide access to the [DBHS and OIFA] office for everyone via a 1-800 phone number
7. The administration should provide oversight and mediation as needed
8. The OIFA should be able to advocate for those that can not advocate for themselves
9. The State should help establish a "Conference Fund" to bring people together quarterly, semi-annually, or yearly for educational, support and advocacy opportunities
10. The OIFA Advisory Committee or Council should be represented at the highest levels of the State administration
11. There should be grassroots connections [from the OIFA] to all members served throughout the community
12. The OIFA should "Go after State Networking Grants"
13. The OIFA should, "develop people's voices and, help people have their voices heard"
14. There should be a focus on education and prevention, starting with youth and children
15. Everyone needs to, "remember who we will be serving and be responsive to their needs"
16. The OIFA needs to report to the Deputy Director or Director of Mental Health Services
17. The OIFA needs to be involved in top management discussions
18. The OIFA needs to be a part of the system transformation. Its "voice needs to be heard at the top level, the message of recovery needs to be heard at the top level"
19. There needs to be funding and compensation to help bring people to the table
20. There needs to be an ability for the OIFA to help reimburse agencies for allowing their people to participate in meetings
21. The Office needs to network in the community, and continue to bring people to the table
22. The OIFA and administration needs to facilitate a speaker's bureau
23. The OIFA should be a clearinghouse for information
24. There should be workforce standardization (training, expectations, policies, and protocols) for Peer and Family Support Programs. These should be monitored through the OIFA
25. There should be OIFA offices and representation within all TRBHAs/RBHAs
26. There needs to be interagency communication between the OIFA and other State agencies
27. The OIFA should provide input to State leadership decisions

28. The OIFA Director should, “Be visible and not four or five levels down in the organizational chart. Community and other State agencies need to see the Office at the appropriate level within the hierarchy”
29. Leaders of the consumer community stated that the OIFA must report directly to the Division Director/Commissioner of Behavioral Health, “which reflects the majority of all OIFAs throughout the US”

Core Principles

Although these were not discussed in depth in the Summit, The Consulting Team also would like to recommend to the DBHS Senior Leadership Team that they should consider several core principles of a successful Office of Consumer Affairs. These are outlined in more detail in a document entitled *Office of Consumer Affairs: A Pathway to Effective Public Mental Health Services*.

These core principles include:

1. The establishment, planning, and hiring of staff for an Office of Consumer Affairs must be supported by consumers
2. The Office of Consumer Affairs must be directed by a self-identified consumer/survivor
3. The Director of the Office of Consumer Affairs must be part of the Senior Management Team
4. An adequate support system for the Office of Consumer Affairs must be established and maintained
5. The Office of Consumer Affairs serves as a systems change agent, and
6. Establishing an Office of Consumer Affairs does not relieve the other senior managers and officers of responsibility for interacting with consumers

Wrap-Up and Next Steps

The OIFA Director ended the meeting by thanking everyone for coming together for the Summit, and stated that leaders are found at all levels of an organization. He closed with a quote by Former President John Quincy Adams “*If your actions inspire others to dream more, learn more, do more and become more, you are a leader.*” He stated that when people went back to their daily routines and schedules, they should go and *help others dream, learn, and do more in their communities.*

REFERENCES

Jorgenson, J. & Schmook, A., (2000). *Offices of Consumer Affairs: A Pathway to Effective Public Mental Health Services*. Washington DC: National Association of State Mental Health Program Directors, National Technical Assistance Center for State Mental Health Planning.