

# **Appalachian Rural Health Institute**

## **ARHI**

### **COMMUNITY HEALTH ASSESSMENT**

#### **Diabetes: Focus Group & Key Informant Findings**

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#### **OVERVIEW of QUALITATIVE METHODS**

Focus groups and key informant interviews were conducted with individuals in Athens, Hocking, Pike, and Vinton County, Ohio during winter and spring quarters 2004. Community contacts were made to identify locations to hold the four focus groups. Session times were based upon availability of a meeting facility. Key informants in each county and snowball techniques were used to locate participants. Eligibility for inclusion was knowledge of varied county health care services, awareness of services available for persons with diabetes, familiarity with health care needs of the general population, and a willingness to participate. Attempts were made to obtain participation from individuals that worked in different community sectors. Participants were employed in local health care services, familiar with health care services and county residents, and most were long time residents of Appalachian Ohio. Explanations of the Appalachian Rural Health Institute project were given and an opportunity for questions was provided. The co-investigators served as the facilitator and note taker of field notes at each focus group. A series of semi-structured questions were used to guide focus group discussions. Sessions lasted approximately one hour, and were taped, but not transcribed. Content analysis was used to summarize the informant interviews and focus group data by county, and themes were identified.

In Athens County, four persons participated in the focus group at O'Bleness Memorial Hospital on May 18, 2004. In Hocking County, the group took place at the Logan-Hocking Library on May 25, 2004. The focus group conducted at Pike County Library occurred on May 13, 2004. The final group was scheduled in Vinton County at the public library in McArthur on June 10, 2004. Participants included home extension agents, pharmacists, dieticians, health educators, registered nurses, a diabetes coordinator, licensed practical nurse, a dietary technician, and a physician.

Additionally, nursing students in the RN to BSN program at Ohio University conducted community informant interviews. Co-investigators directed students to appropriate informants in a single county. A series of semi-structured questions and probes were used to gather data. Interviews lasted approximately 25 to 30 minutes, field notes were kept, and summaries were completed. A total of 20 participants took part in interviews: Athens County (n = 6), Hocking County (n = 5), Pike County (n = 5), and Vinton County (n = 4). Interview participants included registered dietitians, diabetic educators, physicians, medical student, family nurse practitioners, registered nurses, licensed practical nurses, a pharmacist, and a community support person. Findings presented are summarized from the focus groups and key informant interviews in the four counties.

## **COUNTY SERVICES for DIABETIC PERSONS**

### Athens County

In Athens County, informants suggested that some persons have difficulty finding a physician near their home, and others have difficulty locating a physician who was knowledgeable about diabetes management and treatment options. Informants thought that O'Bleness Memorial Hospital, in Athens, has a good educational program in place for diabetics. A medical nutrition program with a dietician consult and Diabetes Self-Management Therapy, a program approved by the American Diabetes Association, are available for diabetic clients. Currently the classes are two days a week, but no evening classes are available for working persons. The cost of the educational class is \$400. A program through the County Home Extension Office entitled "Dining with Diabetes" is being planned to begin in the Fall of 2004.

Informants all suggested that Dr. Frank Schwartz and his office staff are working to bring better diabetic services to the Athens area by working with the local hospital. At this time educational services at Dr. Schwartz's office are free for diabetics due to grant funding. One participant said, "Programs are available in the Athens area and people do not bother to take advantage of them, even when they are free." A common problem identified is that about half of appointments are "no shows" for scheduled times.

### Hocking County

Most diabetic education available in the Hocking County is provided by Hocking Valley Community Hospital. The hospital has created a program that is compliant with the standards set by the American Diabetic Association and it is called *The Diabetic Self-Management Training Program*. The program is keeping records of patient activities and outcomes. Local physicians are noticing improved self-management of diabetes in their patients. One informant said, "This is working far better than we thought possible." Costs for the program are being covered by a grant from the local Moose organization and some additional state funding. This program is provided by a registered dietician and a diabetic educator who is also a baccalaureate prepared nurse. The program is available for persons with type 1 diabetes, type 2 diabetes, and women with gestational diabetics. The program has already provided care for 200 persons with diabetes in 2004. Those in the program complete an assessment and receive initial diabetic education

through a one-day class (9 a.m. to 4 p.m.) that includes 4 to 6 persons. Persons with diabetes attend a seven hour seminar class where things like the disease process, nutrition management, physical activity, medications, hyper and hypoglycemia, self-management, physician care, glucose monitoring, psychosocial adjustment, and goal setting are reviewed. These individuals return in three weeks, goals are reviewed, and appropriate follow-up is arranged. Exercise is often a goal that has not been met. Follow-up phone calls are also part of the program. In the 2 ½ years the class has been operating, only two persons have not completed it. Those participating then have a follow-up visit in 2 to 3 weeks, see a dietician or diabetic educator individually, and are scheduled for regular physician visits to monitor their Hgb A1c. A final visit occurs to see if they have achieved their one year goal and a phone follow-up occurs after that..

Several other health programs assisting residents with diabetes were identified. The Hocking County Health Department administers the Bureau of Children with Medical Handicaps (BCMh) which works with local children that have diabetes. The local hospital and the health department both have occasional free screenings for blood sugars throughout the year. Hocking Valley Community Hospital has consistently participated in the annual county fair by providing a screening tent where they provide diabetes screening and information about diabetes care. One physician has services available in his office to help educate his diabetic patients. The diabetic nurse educator at Hocking Valley Community Hospital stated, “Although all of the local physicians care for diabetic patients, most of the referrals that we see are from two physician offices.” One physician is able to provide services in a facility that uses a sliding fee scale for those without insurance or money to pay.

The Hocking County Health Department receives many questions about diabetes and receives some referrals for care. They are currently caring for three children that have insulin pumps. Most local children receive care from Children’s Hospital in Columbus. Locally, they have had strong support from the persons providing the pumps. Children with diabetes are connected with other families who also have a diabetic child and arrangements are made for children to attend diabetic camp. The health department provides local children with diabetes a CD-ROM that uses a game format to educate them about diabetes. One focus group participant said that children who see physicians regularly tend to manage their diabetes better and those that do not regularly see doctors fail to self-monitor. Issues sometimes come regarding the age when a child should be empowered to provide self-care. Problems experienced by other mainstream families,\* such as manipulation by children’s demands and adequacy of parental discipline and guidance,\* were described.

### Pike County

Informants from Pike County provided information about services for persons with diabetes who are residents of the county. The Family Health Care Center in Waverly provides low cost health care by using a sliding fee scale for charges based upon income. The Center is participating in a national collaborative program that uses a database to track information concerning major health concerns such as diabetes and heart disease. Equipment is available at the facility to provide low cost Hgb A1c levels as needed, as well as diabetic counseling, and financial assistance with the costs of supplies. However, even with this financial assistance, a participant said, “People still struggle to afford what they need.” Lack of attendance at regularly scheduled visits and failure to obtain Hgb A1c levels every three months were viewed as adequate self-management problems.

High costs associated with medicine were viewed as problematic. Bartley Pharmacy works with patients and physicians to find discounts and lower prescription costs.

The Pike County Diabetes Coalition is a volunteer group that tries to work one-on-one to assist local residents care for and cope with diabetes. They try to find sponsors to assure that youth are able to go to diabetes camp,\* and they have a small budget used to help pay for supplies (\$100/person) when no other resources are available. A support group is available at Bristol Village and most meetings have 20-30 elderly persons in attendance, but younger and middle-aged persons from the community rarely attend even though they are welcome. The group was once part of Central Ohio Diabetes Association, but they no longer have this support available. Pike Community Hospital (35 beds) is located here, but has limited services for diabetics. Pike County Home Health is associated with the Pike County Health Department and provides services to diabetic patients when physician prescribed. Bristol Village, located in Waverly, provides a home for approximately 700 retired persons and has facilities for assisted living, skilled nursing care, and a center for those with Alzheimer's disease and other forms of dementia.

Pike County has neither a registered dietician nor a certified diabetic educator available. One informant said, "If there were, it is unlikely that physicians would give referrals." The Pike County Diabetes Coalition tries to provide education and support to persons with diabetes in the county. However, while many older persons participate,\* younger people often do not. A participant said, "The demands of work and taking care of family make this difficult." Only a small number of local persons with diabetes participate in the programs. Several focus group members described a local need for a physician who would take diabetes "under their wing" and work with those in the county that have the disease. It was suggested that local physicians need to be better informed about diabetes and do a better job educating people about the importance of living healthy lifestyles.

### Vinton County

According to the participants in the county focus group, many Vinton County residents are employed in high risk occupations such as logging, saw mills, and farming. Because of the occupational hazards inherent to these jobs, injuries and loss of limbs frequently in the county. Family Healthcare, Inc. is the only medical care service center available for local residents and the only point of service available for persons with diabetes. The center is located in McArthur and open Monday through Friday from 7 a.m. to 7 p.m. At other times, emergency or urgent care is sought in Athens, Jackson, or Ross Counties. An informant said, "We don't have much. We have to refer to Athens or Jackson." An emergency squad is available in the county and staffed 24 hours a day/seven days a week. On occasion, physicians still make house calls. Tri-County Mental Health and Counseling provides services here, but they are overwhelmed with the needs. Ohio University's College of Medicine provides a van that comes into the community for screening purposes. Most of the health care services are grant funded. A diabetic educator from Athens County has visited a few times in the last year and there is hope that monthly visits will continue. The first Wednesday of every month people can go to the Vinton County Health Department and get a blood glucose test or have an Hgb A1c completed. One nurse said, "That is a good opportunity to answer questions they may have." Home health professionals sometimes

see persons with diabetes, but that is only a reliable source of service for persons that qualify for care.

Four physicians work at the Family Healthcare, Inc., but none live within the county. They travel to the clinic from Athens and Chillicothe;\* for example an OB/GYN and midwife come from Athens County. Other available practitioners include a gerontologist and family nurse practitioner. Most care is paid for by Medicare and Medicaid, and a sliding scale is used for those who are self-pay, therefore no one is turned away. The clinic is in the process of recruiting a physician who can also serve as the county coroner. No dentists are available in the county and only a single optometrist is available. Gills Family Pharmacy is the only pharmacy available. While the Family Healthcare center meets the needs of many in the county, the services available are viewed as inadequate to meet all of the county's health care needs. The center provides a Med-Share Program, a patient assistance program with the pharmaceutical companies that provides either free or reduced cost medication. This program enables the clinic to assist about 1500 patients, but this is only 25% of their actual patient load. The center sees 6 to 9 new patients per week who have been cut from Medicaid or disability. The center not only provides for physical needs, but also assists individuals and families to obtain food or clothing when needs arise. A social worker assists with case management.

Physicians at the center inquire about availability to pay for medications and provide samples whenever possible. A team has been established to work with diabetic patients. The Family Healthcare Clinic is doing some computer tracking of persons with diabetes. Approximately 163 persons with diabetes were seen last year with an increase to 185 this year. The program serves a few children with type 1 diabetes, but most patients are adults with type 2 diabetes. The clinic has been working with Dr. Schwartz's office in Athens to establish a protocol for care and education. The clinic does not currently have a regular diabetic education program but is attempting to establish one. The clinic is presently working with the local County Home Extension to provide the "Dining with Diabetes" program. The clinic has established a relationship with a laboratory that will work on a sliding scale. Diabetic clients are provided with glucometers by the clinic and testing strips are available on a sliding fee scale. The clinic is currently working with clients in goal-setting for diabetes self-management, and staff tries to address barriers that limit adherence to care needs. Specialist care for uninsured or underinsured patients that have foot or leg ulcers, retinopathy and dental problems is a challenge. The few patients in the county that are on dialysis seek treatment in Circleville, a drive that usually takes more than an hour each way.

## **DIABETIC HEALTH CARE DEFICITS**

Informants noted several needs related to diabetes care in Athens County. While services for diabetic clients are increasing within the region, more local medical providers need to be aware of needs and management of diabetic care. This concern was echoed by informants in the other three counties. Lack of exercise was perceived as a concern for local persons with diabetes. High costs of joining a fitness center are deterrents for many as they are unable to get outside and walk.

In Hocking County, several things lacking needed for diabetes care were identified. These things include prevention programs related to diabetes, facilities or activities to encourage regular  
Community Needs Assessment, ARHI Project, 2003-2004  
Denham & Rathbun, 2005

exercise, and support groups for persons with diabetes and their families. Most cannot afford the cost of exercise and many live in rural settings where they seem limited in their abilities to participate with others. Many local people with diabetes are on Medicaid because diabetes is considered a disability, thus supplies and insulin are covered. This was also true in the other three counties. An informant that works with persons with diabetes said, “We work with physician offices to assure that no patient has to go without their supplies. Most of the pharmaceutical reps will give patients that are considered the “working poor” free medications and supplies if the physician’s staff alerts them about the patient.” Free glucometers are available for those who cannot afford them; companies use this tactic to ensure that patients purchase supplies for that particular “brand” of device.

In Hocking County, informants expressed a need for greater community interaction to address local health care needs. A nurse suggested that a grant writer would be an asset as many clinicians have limited time for these activities. Suggestions about services and resources that could benefit those living in this county were a dialysis unit, a cancer clinic, a CT scan machine or an MRI machine (currently patients either wait for the arrival of mobile units or travel to another location in order to obtain these services). One nurse thought that a pediatric diabetic specialist would be an important addition to the community’s medical staff. It was suggested that specialists in Hocking County,\* such as an endocrinologist,\* was lacking. A physician who has been a leading proponent in providing excellent diabetic and obstetrical care in this county is leaving the area. In Vinton County, needs identified included a diabetic educator to provide consistent and on-going nutrition and diabetic education, a podiatrist, and an optomologist. The general lack of available services in this county was discussed earlier.

## **DIABETES SELF-MANAGEMENT**

Care needs of persons with diabetes discussed by informants included a high rate of depression, a lack of exercise, and failure to comply with dietary needs. When queried as to whether or not persons with diabetes take good care of themselves, a Vinton County informant said “About fifty-fifty. Some do give an honest effort, others are really in denial.” Several Athens County informants described the multiple constraints faced by diabetic persons in the region that create difficulties in diabetes self-management. While patients initially attempt to take care of themselves, they often quit over time because they perceive it as taking too much effort. Many discussed needs for persons with diabetes to take ownership of their illness and its management.

Athens group members suggested that misconceptions about needed care are often problems. For example, some persons with diabetes think that special foods are needed and do not understand how to appropriately modify diets. The cheapness and availability of “junk” foods makes it difficult for some to alter their diets. Persons with diabetes often have difficulty with food choices and seem poorly educated about dietary needs. A Pike County participant said, “I once talked to a person who thought he could eat all the bananas he wanted at a time.” Another said people do not understand the differences between carbohydrates, proteins, and fats. Someone else said, “Misunderstandings about diet, especially carbs, leads to poor dietary choices.” Another example of dietary misunderstandings described was related to not understanding the differences between natural sugars in fruits versus sugar and sugar substitutes and how to include these in diets.

Pike County participants said that many community residents with diabetes seen in medical visits fail to adequately self-manage their diabetes. Lack of exercise and diets deficient in fresh fruits and vegetables are common problems. One person said, "People on limited incomes think that they cannot afford fresh produce." Another noted, "The style of cooking is an important factor and barrier to good health practices." A Vinton County informant said, "Non-compliance with an appropriate diet is a barrier we often face. Most people just don't know any other way to eat than what they're used to, and they're going to stick with that." Another said, "A lot do try. Some have a why start now attitude. Many just can't see the long-term consequences at all." Lack of understanding often means that persons do not thoroughly understand dietary needs, do not monitor blood pressure adequately, and fail to adequately take care of their health.

Lack of understanding often means that persons do not thoroughly understand dietary needs, do not monitor blood pressure adequately, and fail to adequately take care of their health. Athens County focus group participants said persons with renal disease and diabetes have especially difficult times in understanding the complexity of the diet, and simple resources for teaching patients are often lacking. Other problems related to self-management were the elderly not adequately cooking meals for themselves, general misunderstandings about starches, and family beliefs and practices that are contrary to physicians' instructions. None of the counties had easily accessible or inexpensive programs for regular exercise activities for residents.

Informants described medication concerns for persons who lack health coverage and have limited incomes. One informant said that couples with multiple prescribed medications will often limit what they take in order to save money and many fail to obtain prescribed refills. Several agreed that when persons are confronted with a medication that they cannot afford, they will not take it. An Athens County informant described how she called physicians to suggest generics when they are available if a patient chooses not to purchase medications because of costs. Problems related to Medicare reimbursement sometimes occur when physicians fail to specify a number of refills on prescriptions (e.g., testing strips for glucose monitors). Another Athens County informant said that many people do not know how to properly use glucose monitors and often bring them to the pharmacy. One local pharmacy now has someone available to teach patients how to use glucose monitors and also provides training on how to use a nebulizer for asthmatic patients.

Hocking County focus group participants said that many local persons have problems with health coverage and experience difficulties obtaining diabetic supplies. Patients are often seen who need assistance with obtaining prescribed medications. Some local physicians provide assistance in obtaining medications for indigent persons from pharmaceutical companies. However, most clients need assistance with the long forms needing completion and many find it uncomfortable to disclose personal information. Local persons with diabetes without Medicaid or other health insurance often have difficulty obtaining medical supplies such as strips for glucose monitors. Pharmaceutical companies will not provide strips to outpatient clinics. Families often make choices about which member's health care needs are greater and often try to stretch medications rather than taking them as prescribed. Many younger and older residents get frustrated and angry about their inability to access needed care and "just give up instead of finding help." A local support group for diabetes advertised in the local paper is actually not functioning. While the group was active 15 years ago, in the last 3 to 4 years it has become inactive.

Diagnosis of diabetes in Pike County was thought to be less than the actual number of persons with the disease. One informant reported, "At a recent health screening of over 700 people in the community, 10% were discovered to be diabetics." The focus group participants suggested that many cope with the possibility of having the disease through either denial or underestimating the significance of the disease. Many persons in the region speak of having "a little sugar" and many have a personal philosophy that says they can "eat a little sugar today and tomorrow I'll be good." In Pike County, several spoke about local physicians that told patients they were "borderline diabetics" rather than diagnosing them as diabetic. For example, one informant said she had been told that she was an "early diabetic" and given information that sounded as if the disease would get better. She confessed that she was not taking adequate care in managing her disease. A physician described diagnosing a young teenage girl earlier in the day with type 2 diabetes. She also described an 18 year old girl who denied checking her blood sugars and failed to take the initiative for caring for her disease. A group member discussed a local woman with diabetes who is now blind saying, "No one ever told her how serious diabetes is. It just didn't seem important and so she didn't take good care of herself."

When questions were asked about things that might be helpful in assisting persons in diabetes self-management, a Vinton County participant said "It would be great if we could bring people with diabetes together to talk-- to share ideas, views, and experiences." Another person said, "We need some type of group setting, once a month or something like that, for people with diabetes to meet and talk together." Group support was viewed by many as a potential but lacking asset.

## **MEDICAL MANAGEMENT**

When health care insurance was discussed, problems related to the lack of coverage were described. Informants discussed clients not communicating well, lack of understanding, and some families' lack of home telephone service as other problems in service delivery. Transportation is a problem for many Appalachian families when trying to access care. For example, in Hocking County, a local cab company will go to Haydenville and Murry City but it is costly and all residents do not have access to vouchers for transportation costs. In Pike County, a Community Action program can be arranged to assist with transportation for medical care. An informant said that she provides health care services to two people without telephone service and often has to drive to their homes to check on care needs. High gasoline prices over the last few months have placed additional burdens on families who have low paying employment and inadequate or no health care coverage. Many local people are transported by family members to appointments.

Missed medical appointments are a concern in all counties. A focus group participant from Pike County noted that on some days it is possible that there may be as many as 50% cancellation or no-shows for appointments. Reasons given for failure to keep appointments are things like being "too sick to go to the doctor," no money for gasoline, or lack of transportation. A tactic found to work with diabetic patients by persons in Hocking County is regular phone reminders for patients about scheduled appointments. When appointments are missed, follow-up calls are made to try to reschedule. This procedure has proven fairly successful in cutting the number of missed visits. The hospital out-patient services did a survey and found that use of phone reminders was

effective in decreasing missed appointments. Explaining ahead of time the purpose of the next appointment and what will occur has also helped increase adherence. Missed appointments sometimes mean\* that families have to reapply to cover some children's clinic services. Therefore, efforts are made to assure that the child does not suffer from lack of services.

Focus group members from Pike County agreed that lack of health insurance was a significant problem for many in the county and many people were Medicaid recipients. Payment for medication prescriptions is a concern. Although some pharmaceutical companies have programs available for indigent persons, the group believed that many physicians locally were not willing to complete the paperwork necessary to apply for individuals. Informants reported that compliance with treatment protocols for many diseases including diabetes is impacted when persons have limited incomes and lack health insurance to cover medications costs. A group member said that many local physicians refused to prescribe generic drugs and that a change in this practice would help local residents when cost is a factor. An Athens County informant said, "Type 2 diabetics cannot always get money for monitors or strips, thus they do not monitor their blood sugar as often as they should. People with no insurance have the most difficult time and will frequently do without needed supplies and medications." A Pike County informant said, "Supplies are expensive. Medicare only pays for 50 strips per month [for glucose testing]. This is inadequate."

An Athens County physician noted that when individuals do not understand information about care, they fail to comply with medication and diet prescriptions. For example, "People sometimes think that if they are taking coverage for blood sugar levels that it means that they can eat what they want if they cover it." Pike County informants agreed that many persons do not fully understand information and instructions provided by physicians. Some need assistance with medication charts and most physicians are not prepared to assist patients with these activities.

An informant from Vinton County said a major problem relates to needs for specialty care. Most specialists will not take Medicaid, thus many local people cannot afford to see a specialist and they, therefore, go without treatment. Although primary care is the clinic's main focus, attempts are also made to focus some on prevention and on well-child care. Adults, especially those who are older, only seek care when they are sick. The degree of poverty in the region has fostered a way of life that says "not sick, no visit."

A number of perceptions about the general population may have implications for diabetes care. For example, an Athens County participant said, "Some people would rather purchase cigarettes in the place of medications. Some discussed individuals who sometimes choose to purchase beer or cigarettes instead of medication. It seems as if people do not value their health." Two others said, "Some people have to choose between food and medication." An Athens County nurse said, "Many patients worry about paying for medications and, if the patient is on multiple medications, the concern increases." Supplies are often not paid for by insurance and when persons with diabetes have wounds that need to be treated,\* the cost of care is often prohibitive for them. Informants from Hocking County said that local residents also appear to have concerns about the cost of medication and supplies required. Two informants described circumstances where clients had to choose between the purchase of the medication and payment of personal bills. While an "indigent" program is available for poor patients in the area to receive free

medications through their doctor's office, this may be inadequate to meet many Hocking County residents' needs.

A nurse described a new data collection process where a diabetic flow sheet was being used each time a patient visits the clinic. The flow sheets are used by the staff to assist patients with goal setting and keeping track of self-management progress. She said, "This system allows us to track percentages of compliance so that we can know more specifically what the areas of need are." However, she noted that most people can only afford the lab work once a year and it was still difficult to convince many to get costly services more frequently when they lacked money or health insurance.

Although affording costs of needed medications, supplies, and transportation are problems for many Vinton County residents, they are viewed as especially problematic for older residents. Ability to see an eye doctor and a foot doctor are other needs for persons with diabetes as there are no providers in the county.

### **FAMILY CARE and DIABETES**

The complexity of the disease often results in failure to understand diets,\* and results in irregular Hgb A1c levels. Many informants suggested that persons try to manage their disease, but the complexity of the disease makes it challenging, and reinforcement of education is needed. Individuals with a good support network tend to self-manage their disease better. An Athens County informant said, "Many people with diabetes do not care for themselves properly. The patient with diabetes needs to hear the information, believe it, and want to change." It was suggested that some persons say they are not taking good care of themselves because they are busy taking care of everyone else in the family. When Pike County participants were asked about the ways families support one another when a member has diabetes, there was a consensus that while some patients had supportive families, while others had rather non-supportive ones.

A Hocking County informant said, "We can teach them to exercise and help them make healthy food choices, but this is very difficult for them if the rest of the family maintains the current lifestyle." In families that include one adult member that has been diagnosed with diabetes, the issue of who is going to be in charge of the diabetes is sometimes a concern. Participants in the Athens County focus group suggested that the family member without the disease unknowingly becomes the "food police" as they attempt to provide support. A participant thought that many patients displayed "lack of acceptance and taking ownership of their disease." Another informant stated that she thought what was needed is, "Diabetes education on diet that fits the home-style."

Cultural norms make it challenging to educate the individual living with diabetes. Informants agreed that practitioners must be aware of clients' needs, and tailor programs for specific individual needs. When asked what else was needed for persons with diabetes, an informant from Vinton County said, "The best thing would be if someone could go into their homes on a one-on-one basis and give instructions." The Athens County focus group discussed ways local people take care of themselves when they have diabetes, which indicated a number of culturally significant ideas. Culturally relevant comments made by the group participants included: "many are unmotivated to care for themselves," "patients (mostly women) put others first," and "how do I fit self-care into my busy life." Many persons eat out regularly and require more specific

instructions about how to meet dietary needs. Hocking County focus group members mentioned a lack of motivation to pursue health-related information and a present-oriented attitude in local residents could be problems related to managing diabetes. For example, they suggested that men are likely to ignore signs and symptoms of health concerns.

Athens County focus group members said that,\* when persons are on a restricted diet for diabetes or renal failure, educators need to use what is viewed as a culturally sound approach by suggesting that patients try a “once in a while” approach to eating forbidden or restricted foods. Agreement among these participants suggests that instructions need to be approached from a positive or “strengths” perspective rather than only focusing on limitations or restraints. Hocking County participants said opportunities for one-to-one conversations were the best ways for distributing health information. They suggested an indirect approach worked best in providing health information, first talking more generally, and then inviting or asking health related questions. When local people need health information,\* they generally start with those persons they trust and this often means family members before physicians or other health care providers. Outsiders generally are not trusted and local people tend to only talk with physicians if they believe the doctor listens to them and considers their opinions. They suggested that it is important for patients to feel valued, have an opportunity to express what is important to them, and “not feel overrun in the office.”

Working with families when a member has a health problem can be a challenge. Many participants said, “People need more family support.” In Pike County, some believed that youth with diabetes were over-protected by the adult family members and never learned to self-manage their disease. Several youth in the Pike County community were using insulin pumps and had been referred to an endocrinologist in either Portsmouth or Chillicothe, Ohio. Perhaps 8-10 other adults in the county were on insulin pumps. Health promotion and ways to increase activity were viewed as community needs.

## **HEALTH LITERACY and DIABETES**

Literacy issues often come up when working with local residents. Athens County participants discussed county residents’ problems in getting needed health information, especially related to diabetes. One participant said, “They don’t know that they need information. Some people don’t read and so they don’t know they have a problem.” Several suggested conflicting health messages as problematic. One person said, “Experts can’t agree so how can a regular person know?” Needs for better modes of health education were discussed by the group. One person said, “We need a health educator in every physician’s\* office.” The question “Are there any issues or circumstances that might keep you from learning about your illness?” is often used with clients to ascertain whether or not persons are getting needed information. On occasion, some people might admit, “I can’t read long words” or might say, “I need to get better at reading.” A participant who works with adults said, “I’ve never had an adult say “I can’t read.”” One informant uses food models to demonstrate portion sizes to be sure that clients understand.

Another informant suggested that youth were good recipients for health messages about diet and activity, but the group agreed that role models are needed (including modeling by physicians). Several said that when a diagnosis is first made, people are often not ready to receive the information as they are scared or in shock. It is also true that people often do not want to return

to health care settings for educational programs. Several mentioned that family members sometimes seek information for family members, while the person with health care needs\* may not be interested. One informant said that most patients try to follow whatever the physician has said and not consider asking a pharmacist where they can get additional information.

## **IMPLICATIONS OF FINDINGS**

Appalachian counties have similarities, but also have differences related to availability of services for diabetes patients/clients, access to health care providers, and perceptions about needs of persons with diabetes.

In order to emphasize the improvement of delivery of services to this region of Appalachia, the findings of this report suggest several common barriers related to diabetes care that may have implications for further investigation and intervention. These barriers include:

- Large number of “no-shows” for medical appointments (needs to be better understood)
- Availability of local physicians, specialists, diabetes educators, and other care providers to provide primary care services and education about diabetes.
- Local physicians’ knowledge about diabetes care.
- Assistance to persons with diabetes and their families in identifying long-term consequences associated with diabetes.
- Patient failure to value or believe health care information