Diabetes: A Family Matter

Diabetes Educator Manual

Change How Diabetes is Viewed in Your Community
CONTACT INFORMATION

Diabetes: A Family Matter
Manuals, Toolkit, and Website

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Change the Ways Diabetes is Viewed in Your Community!

All materials can be freely adapted for local use. Please note that they are copyrighted and authors should be credited whenever materials are used. If you plan to adopt the program for local use, please register online on the Diabetes: A Family Matter website at www.diabetesfamily.net to download materials. As you begin using the materials, please return to the Communication section of the website and describe ways you have used the ideas and materials in your program.

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The *Diabetes: A Family Matter program and toolkit* is dedicated to my daughter, Kimberly Malone, who through her life-long battles with type 1 diabetes has taught me much about living with this disease. I also want to thank those people with diabetes and their family members that generously shared their time and stories.
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The development of this toolkit is the culmination of a four year project. While I championed the project and coordinated the efforts, many have contributed to its completion. *Diabetes: A Family Matter* was supported by the efforts of many individuals and groups. I want to thank Chris Knisely, MS, Dr. Frank Schwartz from Ohio University’s College of Osteopathic Medicine, and Dr. Ann Rathbun from Morehead State University. They were instrumental in the early visioning of possibilities of the project and assisted in gaining the financial support that has allowed it to happen.

Initial funding support came from the Centers for Disease Control and Prevention’s National Diabetes Education Program. Additional financial support was given by the Ohio Department of Health Diabetes Prevention and Control Program, Challenge Grants from Ohio University’s Office of Research and Sponsored Projects, Ohio University’s Appalachian Rural Health Institute (ARHI), and the Diabetes Research Initiative (DRI). These funds enabled the development of this project. The project could not have been completed without the continuing support of Ohio University School of Nursing, directed by Dr. Kathy Rose-Grippa, and the College of Health and Human Services, under the supervision of Dean Gary Neiman. Others from Ohio University’s College of Communications and the College of Osteopathic Medicine also provided important support.

Two people deserve special recognition for the huge roles in providing expertise, insight, and skills important for the toolkit development. Dr. Margaret Manoogian has not only worked with me in qualitative research and data analysis, but has been a sounding board whenever I have been frustrated, a consultant about family care, an expert about gerentological and intergenerational issues, a material reviewer, and always a friend. Dr. Ann Rathbun not only gave assistance with the literacy and health literacy reviews of the written materials, but provided continual support by always ‘being there,’ forgiving when necessary, and offering constructive criticism of products and processes. I also want to thank my two daughters Kimberly Malone and Michelle Malone who had to put up with my absence at times while I completed this work. Finally, while my three grandchildren, T.J., Leslie, and Teran, were not directly involved in these efforts, they have been a constant reminder of the importance of family and the need for healthy lives and diabetes prevention.

Others have also played important roles in allowing this toolkit to become a reality. The photographs used throughout the materials represent the artistic talents of Larry Hamel-Lambert. He managed to capture the essence of people as they lived with diabetes in their homes and communities. A special thanks to Amelia Holowaty Krales for the visual design work in the creation of the written materials. The website application development has come from the impressive talents of Joshua Ramey at Ohio University’s Southern Campus. Special thanks to Norm Bebee for his help in designing the program’s logo.

The film *Living with Diabetes in Appalachia* was produced with the assistance of the talented, sensitive, and magical Steve Fetsch. Charles Smith from Ohio University’s School of Theatre played

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an important role by lending oversight to the three theatre students commissioned to write the 
*SUGAR Plays*, Dana Fornby, Nicholas Sgoras, and William Zorn. Thanks to them for their willingness
to learn about diabetes in the Appalachian region and translate these ideas into plays for public use.

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Introduction

This manual is for diabetes educators or persons that will lead the Diabetes: A Family Matter program. This manual suggests ideas about ways to start a volunteer program in a community. Aims of this program and toolkit are to improve health and promote healthy behaviors in a community or group. This manual suggests things to include in a community program. Ideas for recruitment, preparation, and involvement of volunteers are included. Through use of this program, local knowledge about health and diabetes can be increased.

Current and growing trends throughout Appalachia of overweight, obese, and physically inactive people put individuals and families at high risk for diabetes and other chronic illnesses. Evidence about taking personal and community actions to reduce disease risks and increase health is available. However, new ways to motivate individuals and families in local communities to take personal responsibility are needed. This toolkit and program suggest some new ways to approach those that live in the communities of Appalachia.

Diabetes: A Family Matter

Diabetes is a growing epidemic with the numbers mounting each year, especially for those with type 2 diabetes. Although those with type 1 diabetes is a much smaller incidence, health professionals have typically focused mostly on family needs of those with type 1 diabetes. The reason has been that children or youth need help and parents have responsibility for children’s care. The attention given to family needs of those with type 2 diabetes has been much less. The Diabetes: A Family Matter program and toolkit is especially focused on those with type 2 diabetes and their families. A major goal is to help individuals, families, and groups living in Appalachian communities focus on healthy lifestyles and diabetes prevention.

A major goal of the Diabetes: A Family Matter program is to help individuals, families, and groups of people living in Appalachian communities focus on healthy lifestyles and diabetes prevention.

Great strides in diabetes care have been made over the last decades. Even so, a large gap exists between scientific knowledge about diabetes care and what occurs in clinical practice (Glasgow, 2003). However, it is likely that many have outdated ideas about diabetes and its management. All health professionals still may not know about important changes in care practices. At the time of diagnosis, those with diabetes do not always get all the facts they need for good care management. Some do not visit a doctor regularly. Others fail to heed the daily steps needed to prevent complications. Many never attend a diabetes education class. Those that attend a class can be overwhelmed with too much information.

<table>
<thead>
<tr>
<th>Health Beliefs of Local People about Diabetes</th>
<th>List 3 to 4 Untrue Ideas Local People Hold about Diabetes:</th>
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Diabetes is an area of care where some health professionals have specialized education. For example, an endocrinologist is a specially trained doctor with expertise about the glands that control many body systems. Glands, like the pancreas, are involved with diabetes and make hormones that control body activities. Diabetes educators are usually registered nurses, dieticians, or pharmacists. Certified diabetes educators (CDE) have the additional education, skills, and experience needed to care for those with diabetes. All communities, especially many rural ones in Appalachia, do not have an endocrinologist or a certified diabetes educator available. Thus, people must travel large distances to get the specialty care needed.

<table>
<thead>
<tr>
<th>Reasons why Local People Do Not get Needed Diabetes Care</th>
<th>List 3 or 4 Reasons Why Local People get Inadequate Diabetes Care:</th>
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Family history is a strong predictor of diabetes occurrence. In fact, one could say that diabetes is a disease that happens across generations --- grandparents, parents, children, siblings, and grandchildren. If grandparents or parents have the disease, it is likely that others will also acquire it. Evidence shows that family members and friends are often involved in the lives and routines of those with type 2 diabetes. Type 2 diabetes often happens to more than a single person in a family, but family members may lack facts about diabetes prevention.

Many people living in Appalachia enjoy storytelling. In fact, individuals and family members often tell stories about what living with diabetes is like. These stories often focus on problems, hardships, and serious complications. Some stories make it sound as if it is inevitable that bad things will happen. Too often, the stories reflect ideas that nothing can be done. The stories often imply that it is not possible to have a good life if you have diabetes. Some stories seem to say that the disease or related problems cannot be prevented. Some stories tell of helplessness or seeing the situation as hopeless. When this kind of story is told, people may give up trying to live healthy.
Despite the stories that families hear or tell about diabetes, it is a disease that can be prevented or the time before it occurs can be extended. Diabetes can be managed and people can live long healthy lives. For those with diabetes, risks like heart, kidney or eye disease can be prevented, delayed, or controlled. Unfortunately, many in Appalachia do not tell stories about diabetes that includes these facts. Positive stories about diabetes are often lacking.

**Create New Stories about Diabetes**

List 3 or 4 Positive Things You Would Like to Hear Local People Say in Their Stories about Diabetes:

New ways to address the growing diabetes problem are needed. As a family disease, diabetes can be prevented and managed within the home. Self-management is largely about the ways persons with diabetes and those with whom they live form habits and routines. Each day, families make choices and act in ways that impact diabetes management. Finding ways to involve families and community groups is an important step. This program can give diabetes educators, health professionals, and others information about diabetes. It is essential that ways are found to get the messages about the benefits of healthy living and diabetes prevention into the homes and lives of those in the Appalachian region.

**Appalachia: What It Isn’t**

Residents of Appalachia often are stereotyped as hillbillies that are lazy, dirty, poor, feuding, uneducated, and less civilized when compared to others outside the region. Although the Appalachian region has been challenged economically and may have some connections to those stereotypical ideas, its residents should not be labeled. The Appalachian region has a rich history that includes different races and ethnic
groups as its inhabitants. Contrary to popular media depictions, not everyone in the region is the same.

<table>
<thead>
<tr>
<th>Stereotypical Ideas about Appalachians</th>
<th>List 3 or 4 Ways Local People are Labeled by Others:</th>
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Appalachia: What It Is

Prior to the mid-1960s, an identified region called Appalachia did not exist. It was created when the federal government designated the Appalachian Regional Commission (ARC) with legislative powers to address the geographic region of approximately 200,000 square-miles that runs along the northern, central, and southern Appalachian Mountain chain. The Appalachian region, as currently defined by legislation, includes 420 counties, all of West Virginia and parts of 12 other states from New York to Mississippi. Appalachia includes some urban regions, but it is largely rural. People that live here appreciate its beauty and welcome the way of life offered.
This region has made great advances over the past decades. Use of federal funds has improved transportation systems, education, health care, sanitation, and other essential services to help decrease the problems linked with poverty (Halverson, Ma, & Harner, 2004). However, many parts of the Appalachian region are still plagued by high unemployment, high poverty rates, and challenges in meeting resident’s educational needs. Other problems include things like higher rates of disease, lack of health professionals and specialists, fewer accessible health care services, and greater rates of uninsured or underinsured people.

Appalachia is a term used to describe a region in the eastern portion of the United States that stretches from southern New York to northern Alabama, Mississippi, and Georgia.

When compared to non-Appalachian areas, Appalachia has greater health disparities and higher mortality rates from the leading causes of death. Risk factors appear to be highly localized, vary from one Appalachian area to another, and require interventions at the local level (Halverson, Ma, & Garner, 2004a). Links between socioeconomic stressors such as long-term poverty and unemployment are often better understood in terms of geographic region and cumulative effects on health outcomes over time (Brown et al., 2004). This is important because residents are largely a white or Caucasian population. While numbers of minority groups living in this area are smaller, many white people living here have had generations of low paying jobs, frequent problems with unemployment, and great stress resulting from years of poverty.

Type 2 diabetes is a growing national and global problem, one of special concern to families that live in the Appalachian region. While the
incidence and prevalence of type 2 diabetes has been under-studied in Appalachia, some evidence suggests that rates are relatively high, especially in the region’s rural and economically distressed areas. For example, a four county 2004 telephone survey indicated that in Appalachian Ohio, 8.3% of the population had diabetes, a rate that was approximately one-third higher than the national average at the time (Appalachian Rural Health Institute, 2004). A similar, 2006 follow-up study found a prevalence rate of 11.3% in Appalachian Ohio counties, a rate higher than state and national averages (Appalachian Rural Health Institute, 2006). A June 2008 release from the Centers for Disease Control and Prevention indicated that national data show increased diabetes rates in areas of Appalachia traditionally recognized as higher risk for many other chronic diseases, including heart disease and stroke (CDC, 2008a). A review of the literature found that residents of rural regions with type 2 diabetes are more likely to have different needs from those in urban areas (O’Brien & Denham, 2008).

Type 2 diabetes is a growing national and global problem, one of special concern to families that live in the Appalachian region.

People living in Appalachia are not all the same. They vary in their traditions and approaches.
to daily life. However, a culture and way of life associated with many generations of families living in the regions exists. Some speech patterns and ideas about life can be traced to earlier times. Ideas and values often vary from county to county. Family roots are often linked to Native Americans, Elizabethian England, Scotch-Irish, German, French, Italian, Hungarian, Southern Slaves, Melungeon, and other ethnic groups. This rich heritage includes family stories that tell of the immigration to the area and ways a promising life was sought in a new land.

The independence that brought people to the hills and mountains is intertwined with a more modern history, one that continues to influence lives of those in Appalachia. Many are strongly linked to place and family. Many tell stories of family generations living, working, and dying in the region. Extended family, kin, and long-time friends still play important roles in the daily lives of many that reside in Appalachia. Some born or reared in the region move away for a time, but often return home. Those that move away may still value some of the traditions that speak of family and place.

Assumptions Underlying the Toolkit Development

Assumptions impact the ways we see and understand problems and their solutions. It seems appropriate to state the assumptions that influenced the way this program and toolkit were envisioned and created. These assumptions are:

- Diabetes is a growing problem in the geographic region known as Appalachia, a largely Caucasian population where many live in rural places.
- While Appalachia does not have a single culture throughout the entire region, shared traditions and traits are threaded through the lives of many born and raised here.
- Diabetes education and teaching materials targeting the Appalachian population are lacking.
- Family is an important aspect of daily lives of those tied to and rooted in Appalachia.
- Family-focused diabetes educational materials are largely unavailable, but could be useful for individuals and families living in the Appalachian region.
- Primary care seems inadequate to meet the holistic care needs of persons and their families as they live with diabetes.
- Diabetes experts (e.g., endocrinologists, certified diabetes educators, medical specialists) and other health practitioners (e.g., ophthalmologists, dentists, podiatrists, psychologists, psychiatrists, etc.) are not accessible to many in Appalachia.
- Traditional forms of health or diabetes education are not effectively impacting the lived experiences of Appalachia’s families and innovative methods to increase healthy lifestyle behaviors, diabetes prevention, and diabetes self-management are needed.
- Evidence suggests that community programs that include volunteers and target individuals and families have successfully addressed diabetes in other cultural groups where similar forms of social networks and social health determinants exist.
- Excellent diabetes education materials for health professionals already exist with many available for free through internet access.
- Persons that access and use the Diabetes: A Family Matter program and toolkit will have at least basic knowledge about healthy lifestyles, diabetes prevention, and diabetes self-management.
- Diabetes educators living in Appalachia may not be knowledgeable about community or population health, forming to working with coalitions, or the development, implementation, and evaluation of a sustainable volunteer program.
- While broadband access is not available to
many homes in Appalachia, access continues to grow and people in most communities have some internet access through schools, libraries, and health care providers.

- Social networking can take many forms and can be a valuable tool for mobilizing people and groups in rural communities.

**The Diabetes: A Family Matter Program**

This program provides users with materials and ideas about ways to tackle diabetes in local communities. The program and toolkit focuses on diabetes prevention and care management from a family and community viewpoint. Knowledge about local traditions, usual ways of life, and diabetes management has been used to develop ideas that are included.

While all forms of diabetes are of concern, this toolkit mainly focuses on type 2 diabetes. The toolkit provides ways to increase healthy lifestyles and prevent or stop the spread of diabetes and other chronic illnesses. It suggests ways to manage the disease and delay or prevent serious complications. Diabetes educators or other health professionals can use the toolkit to enlist local volunteers and help community individuals and families. As the toolkit materials and activities are reviewed, ideas about the best ways to use them locally can be decided.

These materials are primarily intended for use in rural places of Appalachia. A review of printed and online diabetes education materials has shown that the focus is most often targeted at more suburban or urban persons. Materials that address rural people and include strong ideas about family are often not available. While this toolkit is meant for use with rural Appalachian people, it may still be of use in other regions that share similar cultural patterns. The toolkit may also be of use in suburban or urban centers that serve people that are from Appalachia.

Although this manual is entitled Diabetes Educator Manual, it can also be used by other health professionals. Persons who serve as program directors to guide the local program should have current knowledge about diabetes and its medical management, prevention, and self-management. This program has multiple web-based resources for prevention and health promotion in your community. Materials accessed from the internet are in a downloadable format and links to additional materials are available.

**Additional Web-Based Information Available:**

- Information about diabetes, prevention, and care management.
- Information about family-focused care.
- Health professional resources.
- Information about the Appalachian region.
- Information about others addressing health and diabetes in Appalachian communities.

A unique aspect of the Diabetes: A Family Matter website is the inclusion of a chat forum where you can meet and talk with others who live in the Appalachian region and also have concerns about diabetes. This social networking site is a place to connect with others who are living with diabetes. The communication space on the website is a place to share successful things being done in your community and learn new ideas from others.

**Go to the Diabetes: A Family Matter website at [www.diabetesfamily.net](http://www.diabetesfamily.net) for more information and to find other ideas.**

This Diabetes Educator Manual, the SUGAR Helpers Manual, and the online Diabetes: A Family Matter toolkit provide many materials and ideas for local use. These tools and ideas are intended to be adapted to local needs. If you already have a diabetes coalition or a local diabetes support group then this is likely a good place to share this
information. As you work with other local people, see if you can find ways to use this program to build a healthier community and a strong diabetes program.
COMMUNITY INVOLVEMENT and PROGRAM DEVELOPMENT

» Define the Community
» Leadership
» Finding Other Local Leadership
» Finding Local Champions
» Diabetes Coalitions
» Advisory Group
» Mission
» Program Goals
» Volunteers
» Enlist Community Partners
» Recruit Volunteers and Community Partners
» Raise Funds to Support Your Program
» Apply for a Grant
» Keep Community Partners Involved
Define the Community

You may think no one in your community cares about diabetes, but if you talk with local people you might find this is not true. It is likely that many can identify someone in their family, a neighbor, friend, or co-worker with diabetes. Maybe they have it themselves! Sometimes those that have diabetes are slow to talk with others. They may be private about personal business and keep things to themselves. An aim of this program is to make diabetes more visible in the community, encourage people to talk about their needs, and assist local people to find needed resources for healthy lives.

A first step in creating a *Diabetes: A Family Matter* program is to define your community. The term community is often used to describe people in a town, city, township, neighborhood, or county. The size of a geographic place and numbers of people that live there can describe ways one community differs from another. Sometimes communities are groups of people that share common interests. It is useful to define or describe your community. What is the community you want to serve? Who in the community do you want to help? In order to get started, answer the following questions:

<table>
<thead>
<tr>
<th>The Community You Want to Help:</th>
<th>Those at Risk for Diabetes:</th>
</tr>
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<tbody>
<tr>
<td>My Community is Defined as:</td>
<td>Identify Local People You Want to Help:</td>
</tr>
</tbody>
</table>

What describes the people or groups in the community you want to serve? For example, a local church may want to define community as the members. A local school might define community as the children who attend the school, their parents and other family members, as well as the teachers or administrators working at the school. If you are employed by a hospital or health department, you may define community as the county where you live. You may even want to consider your whole community (e.g., schools, churches, businesses, civic groups, health care providers, local residents). Start thinking about who to involve in your program:
Community Involvement and Program Development

<table>
<thead>
<tr>
<th>Local Groups to Include</th>
<th>Identify 3 to 5 Community Groups to Involve:</th>
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<table>
<thead>
<tr>
<th>Key People to Include</th>
<th>List 2 or 3 Community People from each of these Community Groups to Involve in Your Program:</th>
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**Leadership**

A community diabetes program needs to involve those interested in healthy living and diabetes prevention. Diabetes affects people in the community in different ways. Someone needs to point the way and give direction! Leadership is needed! The person that assumes this role could be a diabetes educator that works in a local health care clinic, hospital, or health department. The leader could be a volunteer that is part of an existing diabetes coalition. The leader might also be a person with diabetes, a family member of someone with diabetes, or any community member that wants to find ways to address health issues. A leader is definitely needed to guide this project! Leaders point the way, but they work with and listen to others.

Maybe you have not thought of yourself as a leader! If you are reading this manual, you are probably viewed as a leader by others. If you have the desire, you can make things happen. Leaders have skills that are noticed by others. Leaders are role models for others and passionate about something that interests them. Leaders can convey information and enlist others in their efforts. Without good leadership, activities flounder and goals are not met.

In rural communities, leadership often falls to those willing to raise their hand and say “I volunteer.” It sometimes seems that a few people are doing all of the work. A leader does not solve problems alone! In fact, good leadership includes others and empowers them to get things done. In small communities, leaders need to invite the help of all kinds of people in the community. Those that live in all aspects of the community need to be involved.
Leadership Traits Needed for a Diabetes: A Family Matter Program:

- Value health and wellness for ALL community people.
- Agreement that health is important and things can be done to improve it.
- Knowledge about diabetes, diabetes prevention, and diabetes care management.
- Enjoyment in doing things with different kinds of people.
- Willingness to get involved with people in the community.

If this sounds like you, you are the right person! If you are not comfortable assuming the leadership role, then ask yourself: “Who in my community could lead this effort?” Some people are shy and may not see themselves as leaders, yet others know they can do the job. Talk to local people about your ideas and offer to work and support them.

1. Identify a Program Leader

2. List names of 2 to 3 People that Might Serve as Leader in Developing a Community Program:

Finding Other Local Leadership

Leadership is best when it is done by a team. Once a leader has been identified, then you will need a team of local people.

Think about others that might help with the development of a local program. Keep in mind that all of the program’s leadership does not have to come from health professionals. Volunteers, stay-at-home parents, retired persons, and others can help!

Activities for Your Local Diabetes Team:
- Sponsor the Program.
- Support the Leader.
- Assist with Resources.
- Propose Ideas.
- Assist with Organization.
- Encourage Others.

Build Your Leadership Team
Identify 3 or 4 Community Leaders to Involve:

It is essential that you select an enthusiastic and competent team of community members to help advocate for diabetes awareness. These local leaders will play important roles in building the capacities of your program. Local leaders can provide numerous networks of people with different talents, ideas, and strengths. They can help spread the word and involve others.

Think about existing community groups that might assist with the program you want to develop. Some of these groups might have money, resources, or members that can also be offered to address diabetes problems and wellness concerns in your community.
Finding Local Champions

A few local champions can help create a strong program. Champions are people from your hometown that get things done! These are the people that step up to the plate and then hit the ball out of the park time after time. They often have large imaginations and big hearts. They laugh easily and have a sense of humor. Champions are those that not only say they care, but their actions show that they do.

Champions are local people that get things done! They can also be people from your community that have moved away and become successful. Champions are people that others look up to and people that can help get things done. Champions can also be local heroes that are willing to speak for your program publicly and maybe even contribute money to help your coalition accomplish goals. Champions and heroes should be people that care about healthy communities and diabetes prevention.

Being a champion is not based solely upon abilities, talents, or material possessions, but rather it is more about how individuals choose to use personal resources. They do not need to be famous, stars, or national heroes! They do not need to have great possessions. All communities have champions that have already emerged and others waiting for an opportunity to shine.

Champions can often see possibilities long before others do. They are willing to take charge. Champions ask questions, find answers, and stand up for their beliefs even when others do not agree. Champions make things happen for themselves and others. They are the ones that not only help you get started, but they are the ones that help you keep going. As you establish your community group, enlist a few champions to lead the way and encourage others.

Think about Your Community, Name 2 or 3 People Who are or Could Be Local Champions for Diabetes and/or Wellness:

Identify Community Resources to Support a Local Diabetes Program:

List 3 or 4 Existing Community Groups that Might Partner with You to Build a Diabetes Program:
**Diabetes Coalitions**

Are you familiar with coalitions? One way to describe a coalition is a partnership among local individuals. A coalition is a formal agreement among people in the community who work together to accomplish a common purpose. Coalitions can offer guidance, direction, and assist in making hard decisions. A coalition gives structure to your diabetes program. Throughout this manual, the terms coalition and program are used interchangeably. Coalition members can help find needed resources. You may already be part of a diabetes or other type of coalition!

If you already have a local diabetes coalition or support group, then you can talk with others about ways the *Diabetes: A Family Matter* program and materials can be used. In the Appalachian region, many diabetes coalitions already exist. If your county is fortunate enough to already have an active one, then you will want to align yourself with them. If you are a part of this coalition then you can share ways this program might fit with what is done locally.

**Identify Leaders of a Local Diabetes Coalition or Support Group:**

Coalitions can be formed for varied purposes. You may have other coalitions working on other community concerns. Talk to some of their members and get ideas for how to create a diabetes coalition. You will want to choose a name for your coalition. *Diabetes: A Family Matter* could be the theme used, but you may want to identify a special name. If you choose to use the name *Diabetes: A Family Matter*, you will find many materials your program can use on the program website. You will also find a logo on the online website that can be used locally. Please note that materials are copyrighted and appropriate credit should be given when they are used.

**Form a Diabetes: A Family Matter Coalition:**

- Identify whether an existing diabetes coalition already exists in your community.
- Share the materials and activities with others.
- Identify who in the community should be part of the coalition.
- Invite interested persons to a start-up meeting where ideas can be shared.
- Decide whether by-laws or policies need to be created.
- Gain needed support and financial resources for the coalition.
- Locate a ‘home’ for the coalition.
- Decide on dates and plans for volunteer SUGAR Helper recruitment and education sessions.

If a local diabetes coalition does not exist, then a first task is to identify community members that can work together. Think about local people and groups interested in healthy lifestyles, diabetes prevention, and diabetes management. Identify these potential supporters.

**Identify 4 or 5 Persons to Help You Form a Diabetes Coalition:**
In any community effort, it is always wise to have some ideas about the kinds of problems you might face. Sometimes, we call things that get in the way barriers. Think about the barriers you might face as you start a local diabetes coalition. If you anticipate these problems then you can be better prepared to cope with them. Barriers might be money, space, expertise, people, or other resources. Other barriers might be things like changing the old ways of doing things or thinking that new ideas will not work. In the Appalachian region, barriers might be things like transportation, geography, isolation, independence, or pride.

Once you have identified the barriers, then you want to find ways to overcome them. Not every barrier can be removed, but many can be if problem solving is used and all work together to find an answer. What steps can you take to overcome the barriers you listed?

### Identify 3 or 4 Barriers You are Likely to Encounter:

### List 3 or 4 Things You Need to Do to Form a Diabetes Coalition:

### List 3 or 4 Things You Will Need as You Start a Diabetes Coalition:

### List a Few Steps You Can Take to Overcome Each of the Barriers Identified:

If you are forming a new coalition, then identify who you will invite to become part of the group. You might be a health professional employed by a hospital, health department, local extension...
group, or other community group. If so, then remember that a stronger coalition can be formed by including representation of other community groups. Take a few minutes and list some groups you want to be represented in your coalition.

**Identify 4 to 6 Community Groups to Include in a Diabetes Coalition:**

Some other things are also important to consider as you think about your coalition. Who will be involved? Will they be permanent or rotating members? Who will comprise the coalition? How many members will be involved? How often will you meet? Where will you meet? You will need to consider how decisions will get made. Who can vote? Whose votes count in different kinds of decisions that need to be made? Bylaws can help you sort out the actions the coalition will take. If you have not written bylaws before, then talk with leaders from other local groups to see examples of what they do. Getting things in order at the beginning is important!

Once your coalition is formed, you will likely need task force groups for special projects. These groups can be formed for a single purpose and then disbanded afterwards. Other task force groups can be formed later as needed. Task force groups provide ways to involve many community people over time. People who have varied interests and learning who in your community are good at different things can help you put together effective groups. Think broadly about the community and invite new people to take part.

Task Force Groups can be formed for a single purpose and other groups can be formed later when needed for other projects or purposes. Task Force Groups:
- Help coalitions accomplish their goals.
- Involve many community people over time.
- Focus on special tasks.
- Can bring new energy and ideas to a project.
- Provide odd ways to support volunteer

**SUGAR Helper Activities**

A presence for the program will need to be established. Consider where your coalition will meet. You will likely need space to store program records and materials. You will need a place to hold the volunteer SUGAR Helpers training program and regular support meetings. You might need places for the volunteers or task force groups to work as they plan, organize, and implement community events. Phone access, a computer, internet, and a way for people to contact you will be needed. Volunteer SUGAR Helpers could help assume some roles once they have been trained if paid staff is not available. As you begin thinking about your program, you will need to make decisions about these things and decide ways to involve others.

**Advisory Group**

If you are just beginning a Diabetes: A Family Matter program and you choose not to form a Diabetes Coalition, then you should definitely consider forming an Advisory Group. An Advisory Group can provide program directions, expertise about diabetes and healthy lifestyles, and networks to community resources.
Diabetes: A Family Matter Program

<table>
<thead>
<tr>
<th>Participants</th>
<th>Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprised of Community Partners, Local Leaders, Diabetes Coalition, Other</td>
<td>Form Local Partnerships</td>
</tr>
<tr>
<td>Collaborators, Local Champions, Hospital, Local Health Providers &amp; Professionals</td>
<td>Identify Local Leadership</td>
</tr>
<tr>
<td></td>
<td>Determine Community Goals</td>
</tr>
</tbody>
</table>

Community Program

<table>
<thead>
<tr>
<th>Participants</th>
<th>Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Educator or Other Health Professional(s)</td>
<td>Finalize Project Goals</td>
</tr>
<tr>
<td></td>
<td>Conduct Volunteer Recruitment</td>
</tr>
<tr>
<td></td>
<td>Provide Volunteer Education &amp; Training</td>
</tr>
<tr>
<td></td>
<td>Provide Volunteer Support</td>
</tr>
<tr>
<td></td>
<td>Provide Project Oversight &amp; Evaluation</td>
</tr>
</tbody>
</table>

Program Leadership

<table>
<thead>
<tr>
<th>Participants</th>
<th>Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local Volunteers</td>
<td>Participate in Training Program</td>
</tr>
<tr>
<td></td>
<td>Identify Personal Goals</td>
</tr>
<tr>
<td></td>
<td>Conduct Local Activities</td>
</tr>
<tr>
<td></td>
<td>Provide Records of Activities</td>
</tr>
</tbody>
</table>

SUGAR Helpers

<table>
<thead>
<tr>
<th>Participants</th>
<th>Roles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Individuals, Families, &amp; Groups</td>
<td>Participate in Local Programs</td>
</tr>
<tr>
<td></td>
<td>Support Healthy Activities</td>
</tr>
<tr>
<td></td>
<td>Improved Health Behaviors</td>
</tr>
</tbody>
</table>
Consider who in your community to include:

**List Names of Persons to Include on an Advisory Group:**

See Appendix A for a place to begin finalizing a list of community people that you might want to consider as coalition members, advisory group members, community supporters, volunteers, and resources. See the flow chart that describes the steps to consider in beginning a Diabetes: A Family Matter program.

**Mission**

People with diabetes come from all walks of life, age groups, and social sectors. As you think about your program, it will be useful to identify the mission. A mission statement is a brief concise statement that identifies the reason a particular program exists and what it hopes to achieve. A mission statement should be meaningful to the group working with the program. Once program or coalition membership is established, a mission statement should be determined. Many online resources are available to help you in writing a mission statement.

**Program Goals**

When you have clear ideas about the local program’s mission, you might next consider program goals. A goal is a short, concise, general statement of the overall purpose of a program. Goals have to do with the ‘reach’ of the program. Another way to think about this is to ask: What do we want to accomplish in our community through this program? You will likely identify 3 to 4 big things. Program goals are the big picture ideas that give your program its direction and help point the way for actions. Goals should be achievable!

Goals help you focus the efforts and activities of your coalition, advisory board, and volunteers.

**A goal is a short, concise, general statement of the overall purpose of a program. Goals have to do with the ‘reach’ of the program.**

**Ideas to Consider for Program Goals:**

1. Enhance the visibility of diabetes and its risks in our community.
2. Increase local knowledge about diabetes risks and prevention.
3. Increase healthy habits of community residents.
4. Train local volunteers to use the Diabetes: A Family Matter toolkit to assist community families adopt healthy lifestyles.
5. Evaluate what is accomplished through the local efforts of our program.

Make your goals specific to what you want to accomplish. Appendix A provides a space for you to begin to identify program goals and specific strategies for ways to accomplish the goals. Strategies refer to the exact steps you will take to reach the goals. Strategies describe the things to do or steps to take as goals are made a reality.

**Volunteers**

A volunteer is an individual who does unpaid work for a program or organization. Since 1989, the volunteer rate in America has increased by 32%. This increase in volunteerism is primarily associated with three age groups: older teenagers (16 – 19 years), mid-life adults (45 – 64 years), and older adults (65 years of age and older). The Corporation for National Community Service is striving to reach a volunteer rate of 75 million by the year 2010 (The Corporation for National & Community Service, Office of Research and
Policy Development, 2006). Americans enjoy volunteering if provided a reason or activity they can value.

In this program, **SUGAR stands for Support to Unite Generations in the Appalachian Region**.

In the *Diabetes: A Family Matter* program, the most important volunteer role will be that of volunteer SUGAR Helpers. In this program, SUGAR stands for Support to Unite Generations in the Appalachian Region. SUGAR Helpers will become the strength of your local program. They will need to be actively recruited and prepared. Much more about volunteers is described in a later manual section and also in the separate SUGAR Helper Manual.

Some Places to Find Volunteers:
- Large Employers
- Local Politicians
- High School Students, Local Teachers, and Others Interested in Education
- Universities
- Senior Centers
- Food Pantries
- Public Library
- Beauty Parlors
- Barbershops
- Laundromats
- Churches
- Fire Departments
- Hospitals
- Doctors offices
- Clinics
- Local Radio and Television Stations
- Grocery Stores
- Restaurants
- Pharmacies

Build a strong volunteer group for your diabetes program. Capitalize on involving people that live in different places, do different things, and have different concerns. Offer opportunity for people with all types of skills, abilities, and resources. Who else might be willing to help? These can be friends, neighbors, and acquaintances from different parts of the community.

List names of 4 to 5 People you Know that Might Help:

Volunteers can be of any age. Those retired may have time to devote to a community program. **Often, the best volunteers are the busiest people.** They may work and already be active in their church or other community activities. They may provide important links across organizations and already know the ways that the community can best be approached. It is important to reach out and involve people that do not always get involved with community efforts. Think of creative and welcoming ways to connect with people from all parts of the community.

» **Local Individuals**
Identify Names of 3 or 4 Other Local People You do Not Know Well, but Might be Willing to Help:

» **Local Health Care Professionals**
List 4 or 5 Local Health Care Professionals that Might Help:
Effective *Diabetes: A Family Matter* programs should involve formal and informal opinion leaders from many different groups and parts of the community. Formal opinion leaders are people with roles that make them community leaders, those on city council, leaders of civic group, or local politicians. When they talk, other people listen! They have legitimate power just because of the positions they hold. Who are these leaders in your community?

**List 3 or 4 People that have Formal Influence on Others:**

Communities also have informal opinion leaders that play roles in getting others involved. These might be local pastors, business people, law enforcement employees, or volunteers in other active community groups. These people motivate others to get things done. They are great at getting things started and keeping them going! Who are these local leaders in your community?

**Identify 3 or 4 People that Informally Influence Others:**

Think about people that have been diagnosed with diabetes. Many of them might welcome a chance to learn more about ways to live healthy lives and get involved with others. They may also have immediate or extended family members that would welcome a chance to volunteer.

**List Names of 3 or 4 People with Diabetes that Might Volunteer:**

**List Names of 2 or 3 Family Members that Might Volunteer:**

Create lists of people to be contacted; this is an excellent way to plan volunteer recruitment. Some people will only volunteer for specific tasks or activities. They may only want to take part in special events, but others that become volunteer SUGAR Helpers will be deeply involved.

**Enlist Community Partners**

Consider ways the *Diabetes: A Family Matter* program can be supported and involve community partners. A community partner can be a person, business, or an organization that provides ongoing support for your program. For example, a health department, hospital, or other local group that provides you space to locate the program could be a partner. It might be someone who provides resources to offset utility costs or provides computers, phone service, or miscellaneous office materials. A community partner may also be a local group that provides
Community Involvement and Program Development

finances to get your Diabetes: A Family Matter program started. A community partner can also be the employer of the diabetes educator or program leader.

**Building strong community involvement is important for success.** Community partners can be concerned citizens that work and live in the community. They can be persons that have moved away, but still have valued connections to the community. They can be local business owners, health care groups, social service agencies, community churches, or other civic groups. They may be local schools or universities. Who could be a community partner for your program?

**List 3 or 4 Potential Community Partners to Support Your Program:**

Large community employers are often interested in wellness and health promotion for their employees and may want to become community partners. Local businesses and groups can give financial support or donations for special events or encourage employees to take active roles in special events you sponsor. Talk with administrators at community businesses and see if ways can be found to partner with them. Employers may be interested in having volunteer SUGAR Helpers work with their employees and/or their families.

**Identify 3 Employers that Might Become Community Partners:**

Always be inclusive when considering community partners! It is good to find persons from all walks of life, those of different ages, and those with different interests that might want to be involved. Be sure to represent the diverse groups that live in your villages, towns, and cities. Think about people from your community. Is there a local hero that has moved away, but still cares about the community? Maybe it is a country singer, a successful business person, a celebrity, a NASCAR driver, a recognized politician, scholar, or scientist? Identifying this person is a way to find a local champion, someone willing to give financial support and help raise local awareness about healthy lifestyles and diabetes prevention!

**Identify 2 or 3 Local People to consider if they Might Become a Community Partner:**

A strong community program will need partners that represent the varied community interests. Do NOT Underestimate what YOU can do! **Appendix B** provides a template that you can use to begin identifying information about persons or groups that could become part of your Diabetes: A Family Matter program. Take time to fill out this form, it will help get you started.

**Recruit Volunteers and Community Partners**

As you develop strategies for volunteer and community partner recruitment, here are some things to consider. First, you do not have to do all of this recruitment alone. Form a core group that can assist you in the efforts. Set your goals. Develop a plan for how the recruitment will be done. Now get started and become the *Little Engine that Could* and form a chorus that says, “I think I can, I think I can” until it becomes “I know
I can.”

Identify 2 to 4 People that Will be the Core Group in Recruitment Efforts:

Second, think of recruitment as an action word! People will not come to you. You must go to them! Prepare yourself well before you begin recruitment efforts. People are often eager to get involved with causes they view as meaningful. People are often willing to work with leadership that is knowledgeable, enthusiastic, and respects their abilities.

Get started and become the Little Engine that Could and form a chorus that says, “I think I can, I think I can” until it becomes “I know I can.”

A critical step for a successful program is the ability to provide messages or information that gets attention and encourages people to get involved. On the Diabetes: A Family Matter website, aids to help construct local newspaper, advertisements, radio, or television messages are located. Posters and fliers to inform others can also be found on the program website.

A number of things can help in recruitment of volunteers and community partners. First, it is important to explain the problem of diabetes.

Ideas for Topics to Discuss:
- Facts about diabetes.
- Challenges diabetes presents to community people.
- High diabetes rates exist in the Appalachian region.
- Ways to support people with diabetes and their family members.
- High risk for serious complications to occur when diabetes is not well-managed.
- High financial costs can occur when persons have diabetes.
- Lack of a national focus on prevention currently exists.
- Inadequate amounts of diabetes education are available for those with or at risk for diabetes.
- Family members of those with diabetes often lack the facts or support needed to help the one with diabetes manage it correctly.
- Diabetes is not talked about much in many Appalachian communities.

Next, be prepared to discuss the mission and diabetes program goals when the programs, activities, and/or events your program will be conducted. On the website, many toolkit materials and activities are available. Choose what will work best in your community.

You will need to explain program goals. The primary ones might be diabetes prevention and to help those with the disease manage it better.

Possible Program Goals Might Be:
- Create a healthier community.
- Be responsible and assist in meeting the needs of community people.
- Inform families about high risks for diabetes because they share genes and routine behaviors.
- Increase the physical activity of community individuals and families.
Community Involvement and Program Development

- Find resources to assist those that lack money or health insurance for needed diabetes care.
- Inform local people about the latest health and diabetes facts.
- Reduce risks of diabetes complications (e.g., blindness, amputation, etc.) for those that have diabetes.
- Assist families to better support members with diabetes.
- Raise awareness about family risks for diabetes and ways to prevent the disease.
- Provide support for those living with diabetes.
- Put a family and community face on diabetes prevention and management.

Also, be prepared to inform people about specific ways they can become involved. Here are some ideas:

- Become a member of the diabetes coalition.
- Serve as a member of the Advisory Board.
- Become a community partner and support or sponsor a local activity.
- Become a volunteer SUGAR Helper.
- Serve on a project task force group.
- Support the program financially with an annual contribution.
- Give a donation for a special event.
- Volunteer for a special community activity.
- Participate in local events and activities.

Finally, be able to clearly explain the steps individuals and groups can take to get involved. Some of these processes will be discussed in greater depth later in this manual. However, decisions need to be made about what will work best for your program and community.

Raise Funds to Support Your Program

Most communities are hard-pressed to find the extra money needed for all programs they would like to sponsor. Once you get started, a budget and financial plan will be needed.

Unless you already have money set aside or allocated for a program such as Diabetes: A Family Matter, you will likely need to find some financial support. Raising money can be a time consuming activity that leads one astray from the main goals. Your program may need to do fund raising efforts later to sustain your program or some aspects of it, but it is not something to focus on at first. However, as you begin a local program, finding seed money to get started will be helpful.

Decisions about ways to obtain funds for local use will be needed. If you are employed by a larger organization perhaps a place to house the program can be provided. However, money for other program aspects may need to be identified. Your coalition and/or advisory group can assist you to figure this out. Knowing what works in your community and who can assist with the budgetary efforts is important.

Once you have recruited and trained your first cohort of volunteer SUGAR Helpers, they could become part of a fund-raising team. However, their main focus is on the diabetes and health promotion work in the community! Formation of a budgetary committee or task force to assist with the financial needs will be useful. Do you have a retired banker, business people, or treasurer from your community that can comprise a budgetary committee? This would be an excellent way to get started.

Applying for a Grant

A grant is an excellent way to obtain start-up or seed monies to begin a program. Money for community projects can be obtained from local, state, federal, and non-profit organizations. Obtaining money usually entails writing a grant application and sending it for review by a funding agency. Grants provide money, but they are usually competitive. Whether you or someone in your
community has grant-writing experience, the first task will be to identify possible funding opportunities and write the application. Possible sources for grants might be local or other foundations, state health departments, other health related organizations, or community groups. If you do not have grant-writing experience, then you might consider enlisting help of a skilled community person.

Every volunteer SUGAR Helper in your community that completes the educational sessions is another voice that can spread the word about healthy living and diabetes prevention.

**Keep Community Volunteers Involved**

Once you enlist community volunteers, it is important to keep them invested in the program over time. Many other ways to volunteer in the community exist. Work with others to find ways to make the volunteer SUGAR Helpers the best known volunteer program in your community! Work with your coalition or other program leaders to make this the local volunteer activity of which everyone wants to be a part. Remember, every volunteer SUGAR Helper in your community that completes the educational sessions is another voice that can spread the word about healthy living and diabetes prevention. Additional information about volunteer activities is discussed in the next section.

**Tips for Continuous Volunteer Involvement:**

- Be realistic in your goals and strategies.
- Include others in plans and let them know others are counting on them.
- Be organized.
- Help people find tasks that they enjoy and can accomplish.
- Be generous with your praise.
- Encourage creativity and leadership.
- Keep things positive as you work alongside others.

**Volunteers Stay Involved Because:**

- They enjoy what they are doing with people they enjoy.
- They believe what they are doing has value.
- They find personal meaning in the activities.

**Ways to Keep Volunteers Involved:**

- Publicly acknowledge those that volunteer and find ways to do this often.
- Show appreciation, a thank you is so important and sincere gratitude is always welcome.
- Let volunteers know how their actions are making a difference locally.
- Let the community know about all of your successes.
RECRUIT AND PREPARE
VOLUNTEER SUGAR HELPERS

» SUGAR Helpers
» Policies for Volunteer SUGAR Helpers
» Roles of a Volunteer SUGAR Helper
» How to Locate Volunteer SUGAR Helpers
» Traits of Volunteer SUGAR Helpers
» Volunteer SUGAR Helper Recruitment
» Volunteer Education and Training Program
» Support Sessions
» Working with Volunteer Cohorts
SUGAR Helpers

In the Appalachian region, people often refer to diabetes as ‘sugar’ or ‘sugar diabetes.’ In this program, as stated earlier, SUGAR stands for Support to Unite Generations in the Appalachian Region. SUGAR Helpers are volunteers that help increase the visibility of diabetes. SUGAR Helpers are ‘hired’ to work in your local Diabetes: A Family Matter program. More about this process is available later in this section of the manual. These volunteers may be health professionals, but they are likely to be persons with diabetes, family members of people with diabetes, or family and friends of someone with diabetes. Anyone in the community can volunteer to become a SUGAR Helper.

SUGAR Helpers are volunteers that help increase the visibility of diabetes.

Volunteers may or may not know much about diabetes, but your program will help them learn what is needed. As you recruit volunteer SUGAR Helpers, training or educational session will need to be planned. During the educational sessions, volunteers will learn about healthy lifestyles, diabetes, prevention, and self-management. More information about this topic is provided later in this section. Your local Diabetes: A Family Matter program will be unique. Although suggestions about educational programs are provided, you will need to decide exactly what to include.

Policies for SUGAR Helpers

Prior to recruiting volunteer SUGAR Helpers, take some time to decide about program policies. If your program is based in a larger organization, you may already have some policies to be considered. If no policies exist, you need to consider what is needed. For example, it is good to know what grounds are in place for ‘firing’ a volunteer in case difficulties occur. Planning ahead can make things easier if problems arise. Volunteer policies should be reviewed during the SUGAR Helper educational program. Establishing policies such as the length of volunteer time period, participation in support meetings, levels of involvement, expectations of time commitments, and reporting of monthly activities can prevent later confusion. For example, will volunteers be volunteers forever once they have completed the educational program or will they need to complete some on-going education each year? What happens if a volunteer drops out after completing training, but wants to return two years later? Having policies in place can assist you if you want to formalize your program. This is a choice that will need to be made. Your organizing team can help you make some of the policy decisions; you do not have to make all the decisions yourself.

You may want to have a policy about how volunteers will be “hired” and “employed.” A job description that describes volunteer qualities can assist you in recruitment. Note experience, skills, and other educational requirements that are important. The job description could include general duties, responsibilities, time requirements, and other volunteer expectations. Even though volunteers do not get paid, if you treat them in professional ways, they always know exactly what to expect. Appendix C provides an example of a job description for recruiting volunteers.

Identify 3 or 4 Things to Consider When “Hiring” Volunteers:
Recruit and Prepare Volunteer Sugar Helpers

“Hiring” good volunteers is a key to a successful program. Plan ahead and list the ‘hiring’ steps for your program’s SUGAR Helpers. Think about ways the application process will occur. ‘Hiring’ a volunteer is a good way to find the right people for the job.

Points to Consider as the SUGAR Helper Team is Developed:
» Identify your expectations for SUGAR Helpers.
» Create a job description.
» Decide how many SUGAR Helpers you want to ‘hire’.
» Set a date for when applications are due.
» Choose times when training for SUGAR Helpers will take place.
» Set aside time to interview volunteer candidates.
» Decide how applications will be reviewed and who will participate.
» Decide how you will decide if volunteers are a good fit with your program.
» Determine who will do the interviews and how final volunteer selections will be made.
» Be able to state the length, format, and time for your educational training program.
» Advertise everywhere.
» Distribute flyers that explain your program and SUGAR Helper roles.
» Know what things you want to discuss and questions you will ask each applicant.
» Use a formal process to notify those not accepted.

Create a special letter to mail to those selected as volunteers. Recognize their unique qualities and thank them for their willingness to participate. Provide each person with a list of others selected to be part of the SUGAR Helper cohort. Include a schedule for the upcoming training sessions.

Another process to consider before you begin your program is record keeping. It is not possible to evaluate the effectiveness of your program without keeping good records. Keeping high-quality records needs attention. Think about the kinds of program records to maintain. A local or school librarian might have some good ideas about how to keep records organized.

As you begin to plan your educational training program, a policy about length, frequency, and content might be useful. Consider expectations about the levels of volunteer involvement. One other thing is to decide the frequency of volunteer support sessions and participation expectations. Policies can help with organization and prevent misunderstandings. Program policies can be presented to volunteers during the educational training program.

Roles of Volunteer SUGAR Helpers
Volunteer SUGAR Helpers create local conversations about diabetes and healthy living. They are the backbone of the Diabetes: A Family Matter program. The primary efforts of volunteer SUGAR Helpers are to spread facts about healthy life, diabetes prevention, and disease management. Volunteers suggest ways families can work together to improve health behaviors. They talk about intergenerational risks for diabetes and ways families and friends can support one another. They work with local groups and share facts about diabetes and help them talk and plan ways to improve health of local people.

Volunteers can also work in a variety of other capacities. You will probably have many ideas about ways to involve them.

Volunteer SUGAR Helpers are not expected to be diabetes experts or educators! However, they can share resources, lead
activities, and help local individuals and families find ways to change behaviors. The SUGAR Helpers' training or educational program will prepare them to talk and lead activities about living healthy lives, diabetes prevention, and diabetes self-management.

**Examples of Volunteer SUGAR Helpers Roles:**

- Share information with individuals, families, and groups about ways to improve health and well-being.
- Help family members learn about diabetes risks when one member or more have the disease.
- Teach the facts to community people about diabetes prevention and its complications.
- Work with others to conduct community events focused on health promotion and diabetes prevention.
- Take actions that make facts about diabetes prevention and diabetes self-management more visible.
- Use the *Diabetes: A Family Matter* toolkit materials and activities to encourage community cooperation to make good health a priority.

After you have read the list of roles suggested, identify some specific ways volunteers can make a difference in your community.

**How to Locate Volunteer SUGAR Helpers**

Most anyone can be a volunteer SUGAR Helper! Volunteers are local people that you may or may not already know. They can be found anywhere. For a strong volunteer program, local people interested in helping others are needed. Great volunteers are found through people networks and word of mouth. Good volunteers are often already busy doing other things. Busy people get things done!

**Places to Recruit Volunteer SUGAR Helpers:**

1. Local churches
2. Participants and leaders in other social groups
3. Universities or community colleges
4. High schools or elementary schools
5. Special community events (like a county fair)
6. Recreation centers
7. Senior citizens groups
8. Hospitals
9. After school programs
10. Friends
11. Neighbors
12. Family
13. Co-workers
14. Business people
15. Persons involved in local government or politics

After you review the list of places where volunteers might be found, identify specific places to begin recruiting efforts.

**List 3 to 4 Things a Volunteer Can Do in Your Community:**

**List 4 to 5 Places to Recruit Volunteers in Your Community:**
As you think about the volunteer program, it is good to think about SUGAR Helpers as a team. Building a strong team is important! An effective volunteer program involves getting the right people on the team. Good teams include people with different talents, abilities, and knowledge. People that are enthusiastic and anxious to get things done are needed. Think about the value of recruiting volunteers from different geographic parts of your community. Try not to overlook anyone!

Connect with a broad network of people to help identify excellent volunteers. Do not assume that because people do not quickly volunteer, they are not interested. In the Appalachian region, people often underestimate their talents and abilities. Give them information about the program and explain how to get involved!

**Traits of Volunteer SUGAR Helpers**

Volunteers can be persons who bring covered dishes to church dinners, those who serve as caregivers, or those who find time in busy schedules to help others. Volunteers are interested in assisting others to have healthy lives. Volunteers may be persons already highly visible in the community or persons less well known to others. Good volunteers may be timid and think they have little to contribute. Encouragement and support is important! As the talents others have to offer are recognized, explain ways they can take part.

**Desirable Qualities of Volunteer SUGAR Helpers:**

- Strong interpersonal skills (friendly, outgoing, positive, caring)
- Good organizational skills
- Interested in taking responsibility
- Able to communicate with others
- Go-getters and initiators
- Willing to learn
- Involved in the community already

**Volunteer SUGAR Helper Recruitment**

Finding the right people to get involved is a challenge, but not an impossible one! Spread the word about program needs in various community places—senior centers, businesses, health care centers, physicians’ offices, church bulletins, government offices, health departments, and local college or high schools. Do not forget places like laundromats, public housing, barber shops, or beauty salons! Consider people who come to events like the county fair or other festivals.

Use a media campaign to inform community persons about the *Diabetes: A Family Matter* program and recruit volunteers to become SUGAR Helpers. Write stories for local papers, use public service announcements on local radio stations, put information on local cable television stations, and place program flyers throughout the community. Target key organizations as you spread the word. Flyers in church bulletins can be a useful way to get out the word. Coalition members can help spread program information.

While fliers, stories in the local paper and advertisements will attract some volunteers, personal contact is often the best. Word of mouth can strengthen recruitment efforts. Talk to local officials about the diabetes problem and tell them how they can help. Some businesses are willing...
to give incentives to employees who are willing to take part in community efforts. Get everyone involved. Develop a volunteer recruitment plan. The plan can include the number of volunteers needed for the program team, specific places to locate persons, and names of potential candidates.

Create a handout to give persons potentially interested in becoming a volunteer and those planning to attend the educational training sessions (See APPENDIX D). This information should identify the who, what, when, and where about your upcoming training sessions.

Volunteer Education and Training Program

Once potential SUGAR Helpers are identified, a training session should be offered. During this time, volunteers will learn more about diabetes, prevention, and self-management. The SUGAR Helpers Manual will be introduced and reviewed. Decisions about the content to cover will need to be made. Although some suggestions are provided, it is best to tailor your program to meet local needs. The content, length, format, and frequency of the volunteer SUGAR Helper training program sessions will also need to be decided. The final decision about the program delivery format needs to be made by the people in charge of the program.

Two important things to consider relate to learning over time and building strong bonds. First, evidence suggests that learning occurs best over time. Learning can be enhanced when it is reinforced. It may be difficult for everyone to make every meeting, so think about the ways time and activities for missed sessions can be completed. It is important that everyone learns the facts and understands how they will be involved in volunteer activities. Second, training sessions allow time for volunteers to get well-acquainted with others and with the program leaders. Forming a strong cohort group (people who go through volunteer training all at the same time) will strengthen your local program and assist in achieving goals. It is suggested that you develop a program that meets over a 6 week time period and each session lasts a minimum of 2 to 2 ½ hours. A policy about the number of sessions that can be missed and ways missed sessions can be made up will be helpful.

Support Sessions

Support sessions are on-going meetings that occur regularly with volunteer SUGAR Helpers. Decisions will need to be made about the frequency of these sessions and their length. Meeting once a month will likely be often enough with a session that lasts a couple of hours. What occurs during SUGAR Helper support sessions? This is a decision to be made by your program, but each session will likely include some educational aspect, business, record keeping, and time for planning or executing activities.

Keep in mind that as volunteers work on activities, they will likely meet in smaller groups or as a whole when completing projects, activities, or events. These work sessions will be different than the support sessions and leaders or coalition members need not be present. However, volunteers will appreciate leaders that staying connected and aware of what

Forming a strong cohort group will strengthen your local program and assist in achieving goals.
is being done. Of course, positive feedback about their efforts is always welcomed. The structure and processes created should be what works best for your community.

**Working with Cohorts**

A cohort is a volunteer group that starts at the same time. A cohort completes training together and works together on activities. A cohort group provides peers with whom successes and concerns can be shared. Cohorts can be natural support systems as teams are formed to work on activities and individual accomplishments or struggles are shared. The ‘hiring’ and training of new SUGAR Helpers is a big time investment. Decide whether to make this an annual or bi-annual event.

Each cohort needs to be oriented and prepared for the roles they will play in the community. Volunteers have different skills, talents, experiences, and levels of knowledge. Some volunteers will be able to work autonomously while others will need more guidance and prompt feedback. Most will have questions. Someone needs to be able to answer them in a timely manner as the training occurs and projects are started.

How big should a cohort be? Your coalition will need to decide what best meets program and community needs. Decisions about numbers of volunteer SUGAR Helpers needed must be made. Careful selection of volunteers is important. Strive for quality and not just quantity!

How many people can be accommodated at a time? What is your ability to supervise and provide timely feedback to those recruited? Time availability and resources are criteria to consider as group size is planned. A cohort of 10 to 15 is typically a good size group to begin your work. However, you might choose to make your group larger if you can only do one educational session per year. A group of 18 to 20 persons is typically the most you can handle well at one time unless you have plenty of assistance to assure that new volunteers learn what is needed and participate fully. If you have a larger group, then you will want to be sure to divide into smaller groups for some activities or you may have difficulty covering all of your educational materials.

It is good to have one cohort trained and active before bringing in the next group. The second time around is likely to be easier because of the experience gained. Earlier cohorts will be working on activities and will likely welcome assistance and new energy. It could be helpful to ask each cohort group to complete an evaluation of each of the sessions and then an overall evaluation. This information can then be used in your final report. It will also be useful in finding ways to keep improving your training sessions.

Remember that the recruitment of new volunteers is also a consciousness-raising activity as the story of *Diabetes: A Family Matter* gets told within the larger community.
PREPARE TO LEAD
VOLUNTEER SUGAR HELPERS

» Diabetes Today
» Diabetes Education
» Standards of Care
» Staying Current
» Primary Care
» Family - Focused Care
» Healthy Lifestyle
» Empowerment
» Power to Prevent Diabetes
» Diabetes Self-Management
» Cultural Competence
» Literacy, Health Literacy, and Low Health Literacy
» Health Information and the Internet
» Communication
» Work with Teams
» Work with Community
» Work with SUGAR Helpers
Diabetes Education

Diabetes education has been shown to positively influence control of blood glucose control and diabetes self-management. When a person is diagnosed with type 1 diabetes, at least one parent or adult family member is involved in this education. However, if diabetes type 2 is the diagnosis, individuals often are expected to manage their disease alone. Because diagnoses of type 2 diabetes increase with age, perhaps we expect these older adults to manage their health concerns without the help of others. Type 2 diabetes is a disease that potentially impacts every aspect of family life. Type 2 diabetes is now being diagnosed in children and adolescents. Many are concerned that the numbers will continue to rise if healthier lifestyle behaviors are ignored.

When a person has type 2 diabetes, family members are often welcome to participate in diabetes education sessions. However, it is not considered essential and a family member is not required to be present. Health insurance companies neither pay for nor suggest that a family support person take part in the education process. Family members are usually welcomed if they choose to attend diabetes education classes. However, the curriculum and educational processes are often the same as when a person with diabetes attends alone. Diabetes education mainly focuses on the medical management of the disease. Less attention is given to family concerns that result from living with diabetes.

It is expected that leaders of the Diabetes: A Family Matter program will be knowledgeable about healthy lifestyles and diabetes prevention and care. Thus, the intent of this manual is not to teach this information. The online toolkit provides materials and activities to engage
a community in addressing the health of its residents.

Standards of Care

As what is known about diabetes and its management continues to grow, standards of care also change. Over the last two decades, persons with diabetes have been able to access new medications and technologies for medical management. Every year Diabetes Care, a journal published by the American Diabetes Association, publishes a new set of diabetes standards. Diabetes educators and medical providers need to review these updated standards and use them as guides for their practice. These standards can be found online at the Diabetes Care website: [http://care.diabetesjournals.org](http://care.diabetesjournals.org).

Staying Current

Where does one go for the latest facts about diabetes today? The CDC National Diabetes Education Program website: [www.cdc.gov/diabetes/ndep/index.htm](http://www.cdc.gov/diabetes/ndep/index.htm) and the Partnership website: [www.ndep.nih.gov/partnerships/partnerships.htm](http://www.ndep.nih.gov/partnerships/partnerships.htm) provide many helpful resources about diabetes education work that is being done all over the nation. Another place to learn more about diabetes data and trends is on the CDC site: [http://apps.nccd.cdc.gov/DDTSTRS/default.aspx](http://apps.nccd.cdc.gov/DDTSTRS/default.aspx).

Identify 2 or 3 Specific Things You Will Do in the Next Six Months to Update Your Diabetes Knowledge:

Primary Care

Primary or patient-centered care is often discussed along with diabetes management. Many definitions of primary care exist, but the term often refers to care provided by specially prepared health professionals. They assess and provide continuing care for persons with signs and/or symptoms linked with illness care, health concerns, health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis, and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.). Primary care aims to provide coordinated and cost-effective care. It also implies patient advocacy. Patient advocacy is when a doctor or health care provider speaks ‘for’ the patient in terms of what their care should be or for resources they might need.

Most agree that primary care is essential for meeting acute and chronic health care needs. Primary care is informed both by scientific evidence and individual values. Primary care supports a medical home for all individuals, a place where a personal clinician uses an ongoing relationship to assure that access and effective care coordination occurs. However, some describe primary care in a more negative
light. They say this form of care actually best serves the needs of the health care providers, as health professionals render care when they want and provide it in ways they choose.

Health care providers seek to give the best quality of care in acute situations, yet care needs are often different when a chronic illness such as diabetes is the concern. Most individuals spend only a few hours in an entire year with their health providers! Some persons with diabetes can spend even less time than that! In fact, most time is spent out of the sight of health care providers. People mainly manage their daily lives within personal social networks. Some give little thought to health and many diagnosed with a chronic illness such as diabetes fail to follow the medical instructions received through primary care encounters.

As important as primary care might be, it is not the only solution for giving the support needed to care for those challenged by diabetes. Another concern with primary care is that it too often ignores many other important factors that impact health such as family, neighborhood, and social contexts. Nurses, diabetes educators, and most other health professionals are taught to focus on individual care needs. Typically, a holistic care focus for the individual includes family considerations. Unfortunately, most actually give little thought or attention to the place of family in the lives of those with diabetes.

**Family-Focused Care**

Family-focused care includes primary care and can be used for acute and chronic care needs, but in this form of care individuals and family members are viewed as the target for care.

Family-focused care is not merely the present! Family retains the memory and historical impact of their past traditions, rituals, and genetics which become important to current and potential health and illness conditions. The impact of current habits and routines not only affect current wellness and disease. Current habits and routines also have implications for younger family members. If we really think about it, the things people do now in terms of their health may potentially influence future generations as well. Family legacy not only applies to genealogy, but it also applies to health, wellness, illness, and disease.

Place is not only a structure where family members reside, but it is also the connected social networks across space or geography. In Appalachia, many live in or near the county where they were born. They pass the school they attended as children, They still have friends they knew in grade school, They often visit the cemetery where family members are buried. Some others have extended family members

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In Family - Focused Care, individuals and family members are viewed as the target for care.
nearby, and many people in the region know their neighbors. Notably, place could also be considered the heart of the family! It is the connection members have with one another even when they are not in that ‘place.’ Family-focused care implies that even when family members are not present, they are never absent from the lives, care, and needs of their family members. In family-focused care, individuals and families are seen as care partners, treatment partners, and recovery partners.

Family-focused care recognizes that the family is a constant in individuals’ lives. Thus, care needs to create partnerships among individuals, families, and health professionals. When the problem is diabetes, individuals and families primarily cope with the challenges in their homes and communities. Family needs to know the facts about diabetes and healthy behaviors. Family members need to understand why changes should occur in daily routines. In Appalachia, many routines connected with diabetes self-management are connected to family members that live in another household nearby. Persons with diabetes rely on immediate and extended family members for support. Some of the other things family members need to know are (a) the best ways to provide support, (b) action steps for making behavior changes, and (c) ways to communicate effectively with one another and health professionals.

Family-focused care recognizes that family members are a constant in individuals’ lives. Thus, family members must be considered in healthy lifestyles and diabetes self-management.

Family-focused care alters the ways diabetes care, education, and support is provided. For example, in family-focused diabetes education, the educator becomes a collaborator (or teammate) and a coach that empowers the family team to work together. Family members set achievable goals. Family members need guidance in ways to support one another as effective diabetes self-management occurs and complications are prevented. Family members are part of the team and, like the member with diabetes, need to understand about prevention and diabetes management. When family fails to understand or lacks the facts, then support networks are threatened (Denham, Manoogian, & Schuster, 2007).

List 3 or 4 Ways You Can Alter Your Present Practice to Provide More Family-Focused Care:

Literature Supporting the Importance of Family in Diabetes Care:

1. A significant portion of diabetes management takes place in family or home settings (Fisher et al., 1998); therefore, many self-care behaviors perceived to be cared for by individuals with diabetes
diagnoses are actually carried out by the patient-family team (Coyne & Smith, 1994; Fisher et al., 1998).

2. Family support has been associated with treatment adherence, illness adaptation, and blood sugar control in studies of individuals with diabetes (Cardenas et al., 1987; Garay-Sevilla, et al., 1995; Primomo, Yates, & Woods, 1990).

3. A framework of effective disease management requires assigned roles as part of routine practices with different family members responsible for different aspects of care (Fiese, 2000).

4. When dietary routines of families with a member with diabetes were studied, findings indicated that gender influenced the kinds of family support offered and cultural food preferences, family traditions, and intergenerational dietary patterns influenced behavior changes (Denham, Manoogian, & Schuster, 2007).

**Family-Focused Health Care Services:**
- Initiates interactions where family participation is welcomed, encouraged, and facilitated.
- Provides care that uniquely meets individual and family needs.
- Gives respect for individual and family preferences, values, and priorities.
- Listens and responds to questions and needs.
- Responds to the distinct and changing needs of Individuals and families over time.
- Takes action for concerns and issues individuals and families view as priorities.

**Attributes of Family-Focused Diabetes Education:**
- Intentional inclusion of family members.
- Genuine levels of interaction between providers and clients.
- Adaptive teaching styles, strategies, and content to distinct needs.
- Valued information provided to family members of persons with diabetes.
- Connects family with needed community resources and support.
- Addresses real life problems (e.g., physical, psychological, emotional, social, sexual, conflict, etc.)
- Attends to intergenerational and developmental needs.
- Respects diversity within and between families.
- Provides coordinated care over time.

Family-focused care demands partnerships between health care providers, the person with diabetes, and their family members. In rural places, clinicians typically are well-acquainted with local family groups. Family-focused care can entail relationships that extend over many years. Family-focused care has potential to provide individuals with supports that might be lacking in primary care. Diabetes educators that understand principles linked with family-focused care know that diabetes impacts the entire family. A diabetes educator use of a family-focused perspective can empower families and communities to work together in achieving healthier lives. Empowerment means that families and communities have within them what it takes RIGHT NOW to be able to help people live healthier lives.

**Healthy Lifestyle**

It is essential that you and the *Diabetes: A Family Matter* volunteers fully understand healthy
lifestyles and wellness. If your local hospital or other community group has a wellness program, you might want to invite them to do a presentation during one of the SUGAR Helpers training sessions. The inclusion of a ‘healthy lifestyle’ session into each of the six training sessions could assist. This would reinforce information and aid learning. It is critical that you and your volunteers commit to healthy lifestyles in order to encourage and support others in making similar changes. Working with coalition members along these lines can also be useful.

### Some Traits of a Healthy Lifestyle:

- Being active.
- Getting plenty of rest and enough sleep.
- Eating foods that keep one healthy.
- Not smoking or using tobacco products.
- Coping with or managing stress and tension.
- Not drinking too much alcohol.
- Using prescription drugs as the doctor ordered.
- Not using ‘street drugs’ or illegal ones.

Changing behaviors is never easy. At the first volunteer educational session, challenge them to set a personal health behavior goal, one they believe they can achieve. The volunteer goals are two-fold. First, it is important to impart useful knowledge about health behaviors and prevention. Second, volunteers need to learn about goal setting, the development and use of action plans, and ways to maintain changes in personal health-related behaviors. Volunteers need to understand what is involved when a person with diabetes or other chronic illness must alter lifestyle patterns and adopt new routines. Helping volunteers understand the difficulties will improve their effectiveness as they work with others and enhance abilities to empathize.

You will need to model behaviors for them. As you assist them to set goals and action plans, you can model these things for them. If you work together in meeting desirable health goals, you and they will gain personal self-confidence. Making a public commitment to goals linked with healthy behaviors changes encourages us to try harder to meet them. You may want to discuss ideas such as doing a more moderate activity if the primary goal cannot be achieved, maintaining goals over time once achieved, and not allowing mishaps or slip-ups to prevent them from progress toward meeting the goal.

### Identify One Healthy Goal You Will Work on During the Next 7 Days (Be specific about the action, where it will occur, frequency it will occur, length of time involved, and degree of confidence you have to do this):

### Empowerment

Empowerment refers to increasing the abilities and capacities of individuals, families, and groups in ways that help them make choices that result in desired actions and outcomes. It affects the way we think about helping and
how we define success. Empowerment occurs through relationships when power is transferred from one person to another. Empowerment equips people with the skills, knowledge, and tools they need to succeed and makes change happen. Not just any change, but changes that are in the direction of the goals they want to achieve.

Empowerment prepares individuals and families with the information and resources to address their self-management needs for healthy living and diabetes prevention or care management.

When it comes to diabetes self-management and empowerment, the diabetes educator needs to approach the person with diabetes without a pre-determined agenda. This is not easy for educators to do because previous learning has said that people with diabetes must have education about a list of very specific content areas. In fact, educators often act like cookie cutters trying to make sure that each patient or client encounter is the same. Rather than individualize or address the uniqueness of individuals, education sessions often become a race with time as attempts are made to cover every topic imaginable. Too often persons with diabetes are left in the dust! They may suffer from information overload and not have learned anything that really meets their personal needs.

Empowerment gives the control to the person with diabetes and asks: What do you want to know about diabetes? What do you need to manage it? How can I best help you answer your questions and address your priorities?

Empowerment gives the control back to the person with diabetes and asks: What do you need to know about diabetes? What is your experience with diabetes? What goals are important to you? Do you have what you need to accomplish those goals? The diabetes educator then responds to the needs and priorities of the person with diabetes! Rather than tell the person living with diabetes what we think they need to know, we answer the questions that are important to them. Diabetes educators that are sensitive, caring, willing to listen, and sincerely try to address concerns are likely to be most effective in meeting actual needs. Being empathetic and permitting oneself to understand the opinions and views of others are essential in an empowerment model.

People are Empowered When They Have:
- Knowledge to make good decisions.
- Control.
- Resources to implement their decisions.
- Experience to evaluate the effectiveness of their actions.


If the topic of empowerment is new to you, it might be helpful to spend some time learning more about these ideas. When family-focused care is the intention, persons with diabetes and their family members will probably find use of an empowerment model most helpful. This means that the educator must move away from thinking about compliance and non-compliance! When those ideas are used, the educator is in control and judges the effectiveness of actions. Educators see bad things happen and they want to see those things prevented. They want people with diabetes to know that it is serious! However, an educator with this point of view often appears to be the enemy or a judge rather than a friend and supporter. Persons with diabetes...
and family members have more control and what they need from educators is direction and support.

Key Empowerment Concepts to Include in a Family-Focused Model:
- Individuals with diabetes and family members choose learning needs and goals.
- Individuals with diabetes and family members make decisions and guide education process.
- Individuals with diabetes and family members know most about their needs and problems.
- Failures are viewed as opportunities to learn and improve care measures.
- Self-management looks for the best ways to identify actions that work and find ways to reinforce them.
- Individuals with diabetes and family members are responsible and accountable for the care.
- Individuals with diabetes and family members need to form supportive networks.
- Individuals with diabetes and family members need to understand the best ways to use their resources.
- Diabetes educators can be guideposts as they assist individuals with diabetes and family members as they move at their own pace toward health and wellness.


List 3 Ideas about Empowerment and Diabetes Self-Management Important to Teach Volunteers:

Power to Prevent Diabetes
Teaching individuals, families, and community groups about ways to prevent diabetes is needed. If we hope to slow the numbers of people diagnosed with diabetes each year and increase healthy behaviors, efforts must be made to spread the word in local communities about the risks and ways to avoid them. You may already have curricula that can be adapted to educate your volunteer SUGAR Helpers. However, volunteers will need other forms of information as well in order to assume their SUGAR Helper roles.

If you do not have a prevention program that you already use, here is information about one you can obtain and adapt for local use. This new curriculum was recently developed by the CDC’s National Diabetes Education Program to help educate African Americans about ways to

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index.htm Search on the internet for the work about empowerment by Martha Funnel, MS, RN, CDE and Robert M. Anderson, EdD and many professional papers will become available. Books on this topic are also available for purchase.
Prevent and manage diabetes through healthy eating and physical activity. The resource titled *Power to Prevent* provides community-based organizations, faith-based communities, diabetes educators, and other program leaders with a step-by-step resource to help make healthy lifestyle changes. Although people of color are fewer in some parts of Appalachia than in some other parts of the nation, many African Americans live here. This resource might be useful for those working with all persons in the Appalachian region whether White or Black. Some materials relevant to your community may need some adaptations.

You can obtain a free copy of the *Power to Prevent* curriculum from: [www.cdc.gov/diabetes/ndep/power_to_prevent.htm](http://www.cdc.gov/diabetes/ndep/power_to_prevent.htm). Other resources relevant for Blacks, Hispanic/Latino, and Asian American groups can also be found on the CDC National Diabetes Education website.

### List 3 or 4 Ideas You have about Ways to Include the Topic of Prevention in Volunteer Educational Sessions:

### Diabetes Self-Management

In the past, educators often spoke about compliance and non-compliance when referring to individuals with diabetes. These terms often meant that judgments were made based upon medical indicators (e.g., blood glucose level, weight, food choices). Because of these negative assessments, individuals and families often felt discouraged and experienced personal blame and shame. As a consequence, we began to use the terms adherence and non-adherence. Although these terms were intended to be less critical, they also were perceived negatively by individuals and families.

Today, we focus on using language that addresses diabetes self-management. By using this term to discuss diabetes, it can more easily be understood that diabetes care is a daily occurrence. The term self-management can be a bit troubling if we think from a family-focused perspective. Many think this means you have to do it all yourself! However, a better way to understand self-management is to see that care management switches from the medical provider to the person with the diabetes. Because persons with diabetes and their family members are forever connected, the self-management really becomes a family household concern. From this perspective, all can see that a shared responsibility exists among the person with diabetes, the family as a whole, and the health care providers.

### Tasks of Diabetes Self-Management:

- Use problem solving to take care of and manage diabetes.
- Identify specific actions to do on a daily or regular basis.
- Manage your knowledge needs.
- Pay attention to your emotions.
- Include family members in all self-management steps.

In self-management, just as in real life, some days are more successful than others. It is important to take a look at the big picture rather than a smaller one! For example, in the
big picture we hope that A1C is lower than 7. A smaller picture is that once in a while a bad day occurs where diabetes is out of control or we eat too much or we do not have the chance to be as active as we want. Short-comings in some areas should not imply failure. Self-management includes several different care areas that require attention. For example, a person may have success in areas of medical management and take prescribed medications, but may not get the amount of daily activity needed. They may reduce the portion size and eat fruits and vegetables regularly, but fail to see their dentist or eye doctor annually or only take medications for hypertension sporadically.

Educators can assist individuals and families who struggle with diabetes. As attention is moved from critical responses about failures to a focus on accomplishments, individuals and families can gain confidence in their abilities. Diabetes educators can empower others to take small steps in the right direction. Even if mistakes are made, support to establish attainable goals can be accompanied with actions plans individuals and families believe they can achieve. Self-management recognizes that you cannot always be effective in changing everything at once, but priorities need to be set and differentiated from long-term goals. Today’s diabetes educator is a collaborator, a team member, and/or a coach.

Self-management is a shared responsibility existing among the person with diabetes, their family as a whole, and their health care providers.

Dr. Bill Polanski, author of several books about living with diabetes has recently highlighted the idea of “worthwhileness.” It is important for persons with diabetes to realize that diabetes management is worth the effort. He describes four important connected messages:

- Personal meaning
- Hope
- Efficacy
- Self-efficacy.

Persons with diabetes and their families can have hope because even small improvements can make important differences in diabetes management.

List 3 or 4 Things You Can Do as You Work with Volunteers to Understand Diabetes Self Management:

Cultural Competence

Cultural competence can be described as the ability to work effectively with individuals from different cultural or ethnic backgrounds. Some disagree about whether Appalachia is a distinct place and whether it has a unique culture. The persistent images of Appalachia shaped by 19th century writers as a place where caricatures of feuding and whiskey-drinking mountain hillbillies dwell still linger. While the
accuracy of these stories was never questioned nor evaluated, the fiction written to entertain continues to be unquestioned by many across the nation. Many people born and raised in the Appalachian region have little or no connection to these images and most find them outside their personal experiences. Unfortunately, these stereotypes remain and continue to be ideas held by many outsiders.

It is important to separate stereotype from reality! Much like other places, Appalachia has great diversity. Some might question whether distinct cultural traits actually exist in the region. Others will likely say that these traits do not uniformly describe the region’s people. Still others might say that too many differences exist within the geographic region of Appalachia to ever say a shared or common culture exists. During the volunteer SUGAR Helpers educational sessions, it will be useful to explore the myths and realities of cultural ideas.

### Cultural Traits of Some Appalachian People:

- Family oriented
- Attached to place
- Value independence
- Modest
- Kind, friendly, and outgoing
- Patriotic
- Proud people
- Less confrontational
- Enjoy good humor and storytelling

Changes have occurred and continue to occur throughout Appalachia. The history of earlier immigrant populations that settled along the Appalachian Mountains is less visible in the lives of people that now dwell here. While many hold to traditions and still include practices and ideas of earlier people, most are influenced by mainstream notions. Newer settlers in Appalachia have brought other lifestyles and patterns. For example, Appalachian Ohio has many Amish and Mennonite settlers, people with many distinct cultural traits. During the spring, summer, and fall, migrant Hispanic workers work in farming industries. Other Appalachian communities have had an influx of Hispanic, Latino, and Asian settlers. Southern Appalachia has large numbers of African American residents. These settlers may have distinct cultural needs, but some of the ways may be adapted by others in the region and vice versa.

Much of the Appalachian region is rural, but some larger cities are located here also. For example, places such as Pittsburgh and Birmingham are urban cities. Some cities have had large populations of people that have migrated there from Appalachian regions. Places such as Cincinnati and Columbus in Ohio are places where many people have roots tied to Appalachia. Other places such as Parkersburg and Huntington in West Virginia or Ashland in Kentucky are not nearly as urban as some cities in the rest of the nation, but they are some of the largest cities in the Appalachian region. It is good to recall that many people that live in cities may come from other places, but some will have moved from rural Appalachian places. This program and toolkit might be useful if working with people who have a history linked with the Appalachian region. However, those living in Appalachia from other places in the nation or the world may not be as likely to relate to the toolkit materials.

Becoming culturally sensitive and understanding culture is important. Working with and within communities requires some competence in understanding one’s culture and a sensitivity to those of others. The materials and toolkit activities included in the Diabetes: A Family Matter program are intended to be
culturally sensitive to those in Appalachia. Cultural traits tied to Appalachian traditions need to be considered in the development and use of health education materials (Denham, Meyer & Toborg, 2004), but they may not be appropriate for everyone. Other information about culture and Appalachia can be found on the program’s website.

Enhancing Cultural Competence:
- Develop awareness of personal fears, biases, stereotypes, and prejudices.
- Appreciate diversity and what this means in terms of cultural norms, beliefs, attitudes, values, and behaviors.
- Learn how others ideas about culture differ from yours.
- Engage in activities and events that allow you to learn about other cultures (e.g., attend cultural events and festivals, travel, read, take classes and seminars, etc.)

List 3 or 4 Important Things You Will Discuss with Volunteers about Culture Relevant to Your Community:

Literacy, Health Literacy, and Low Health Literacy

Literacy is the ability to use printed and written information to function in society, achieve goals, and develop knowledge (U.S. Department of Education, 2006). Nearly half of adults read at basic level, and one out of five of the nation’s people read at or below fifth grade level. Evidence exists that literacy is linked with health status. This could mean that persons with low literacy are less likely to know how to care for diabetes effectively. It is important to consider literacy as you work with volunteers and community persons. Keep in mind that many people only read at a 6th grade level or lower.

Needs of Those with Low Literacy:
- Explain things clearly in plain or simple language.
- Use examples when explaining technical ideas or concepts.
- Focus on key messages and repeat important facts.
- Listen more to questions or concerns and speak less.
- Encourage and answer questions. Watch for cues that indicate reading difficulties (e.g., slowness in completing forms or reading, unable to see, incomplete forms, etc.).

Health literacy is the degree to which individuals can obtain, process, and understand basic health information needed to make appropriate health decisions (U.S. Department of Health and Human Services, 2000). One can be able to read, but still not understand medical terms. Many people from different backgrounds and educational levels get confused about word meanings when they talk to doctors or nurses. Some may have trouble recalling information, especially if ideas are new to them. Be sure to explain carefully whenever people are hearing new things for the first time such as when they are just told about a diagnosis, complication, or new treatment to start. It is easy to become stressed when presented with new information. Also, some medications have potential to cloud thinking and understanding.
Literacy is often described as the ability to read and write, but it also implies that persons can function in the places where they live, achieve personal goals, and understand facts that are important to their lives.

**Health Literacy Means:**
- Persons know where to get the health information needed.
- Persons are able to understand the health information.
- Persons are able to use health information.

Low health literacy is the term used when people have difficulty understanding medical terms or words linked with disease, illness, and medical treatments. Those familiar with ‘sugar’ may be confused about what is meant if the words diabetes or diabetes mellitus or type 2 diabetes are used. Even well-educated people with high literacy levels may have low health literacy. It is important to not assume that because a person is well-educated that they understand medical terms. Take time to carefully explain ideas in simple words and language.

We also need to be concerned about written messages. Health care professionals often give persons flyers, pamphlets, or brochures to read later. It is important to check the literacy level of information given. It is also essential to consider the suitability of information given. Sometimes, health care providers give written information to people just because it is available. It is important to consider whether what is given to individuals addresses their needs. It is always good to briefly review what you are providing to see if this material is appropriate. Too often materials given are of little use and wind up being put in the trash because they are too difficult to read or do not address problems. Many techniques can be used to address concerns with literacy, health literacy, and low health literacy. It is important that all health or illness information is clear and suitable.

**Important Points for Written Health Care Messages:**
- Limit messages to 3-4 main points per document.
- Leave out unnecessary information.
- Use short sentences.
- Give messages in action steps.
- Put information in a logical order.
- Use headings and bullets to divide information.
- Make language culturally appropriate for the group you want to reach.
- Define technical terms in clear language.
- Use visuals to explain messages and put them near related text.
- Include white space.
- Use print that is at least 12 points.
- Highlight important information with bold, underline, or text boxes.

The Partnership for Clear Health Communication is a group that is working to improve safety in medical care and health care systems. They have special concerns about the ways people talk and listen to one another and mistakes made in medical care. They have created a program called *Ask Me 3*. They suggest asking health providers three questions at every health care visit.

**The Ask Me 3 Questions Patients to Ask Doctors and Others:**

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?
Identify 2 or 3 Ideas to Discuss with Volunteers about Literacy and Health Literacy:

**Health Information and the Internet**

A wealth of information is available on the internet, but sometimes you have to wade through a lot of information to find exactly what you are trying to locate. The *Diabetes: A Family Matter* website (www.diabetesfamily.net) contains links to many resources you might find helpful. This could be a good place to begin your search. A chief concern in using the internet for health information is to know what sources are reliable and how to evaluate them.

**Tips to Consider about Health Information found on the Internet:**

1. What is the credibility of the Information?
   - Who uploaded the information provided on the website?
   - Is the source of the information identified?
   - Can you find a date for the last update?
   - Is the information current?
2. Is the content accurate and complete?
   - Is the provider of the information viewed as an expert?
3. Who created the information?
   - Web addresses ending in .org, .gov or .edu are often more credible resources.
4. Is the website well designed?
   - Is the site easy to find information?
5. Can you find a way to communicate with the author(s)?

List 3 Things about the Internet and Health Information to Include in Volunteer Educational Sessions:

**Communication**

The way we communicate and carry information from the sender to the receiver is important to consider. As a diabetes educator, the ability to speak with a variety of individuals, families, and groups is important. You communicate by talking in person or by phone, writing and emailing, and maybe even sending text messages. As a leader of a *Diabetes: A Family Matter* program, you might be talking with other health professionals; speaking with community, business, and policy leaders; interviewing and recruiting local people; teaching individuals, families, and groups; speaking in front of community groups; and talking to special community citizens.

The ways you speak with these different groups is important. Communication occurs in both verbal and non-verbal ways. The distance we stand from one another, eye-contact, touch, and body language are examples of things that provide unspoken messages. Our verbal messages carry meanings and convey feelings. The sound of our voice, the pitch, gestures, and facial messages all come into play when we try to communicate with others. People often read non-verbal signs differently than they hear or
understand our words.

Volunteer SUGAR Helpers may need some assistance with communication skills such as talking to people about the program goals and sharing information about healthy lifestyles and diabetes prevention and management. Using some time during their education sessions to focus on these skills will likely be useful.

Nurses, dieticians, and other health care professionals do not always get special training about good communication techniques. For example, health professionals may know ways to do patient teaching, but be less prepared to teach a family or a large group. Public speaking is different than teaching a class. Learning more about the ways others receive you and your message will be helpful. The things we intend to say may not always be what others hear. Private and public speech usually requires different technique and forms of interaction.

Volunteer SUGAR Helpers may need to learn good ways to talk with family members about healthy lifestyles and setting personal goals. Be sure to review some toolkit activities about things families can do to increase their health.

Consider culture during interactions with others. It is important to recall that people are individuals, yet culture can influence the ways messages are conveyed and received. For example, in Appalachia, some people are less likely to have continuous eye-contact. While many people in the region are comfortable with sustained eye-contact, others like to divert their eyes. This trait is learned as a child and often endures unless an effort to change it is made. Eye-contact is often interpreted in culturally understood ways. Thus, it is possible to misinterpret something being said because of body language. In Appalachia, another cultural trait of many is taking a rather non-confrontational stance. This means that when people do not agree with you, they are not likely to tell you. This non-agreement can mean that they do not return to a doctor or follow given instructions if not viewed as useful. Persons living in Appalachia that move here from other places may communicate differently than those born and raised in the region. It is important to learn about and understand different forms of communication.

Volunteer SUGAR Helpers may need to learn more about talking to groups of people. During their education sessions, discuss some ideas about programs and ways to involve community people in local projects and events. Review a few toolkit ideas that can be used with local groups where volunteers already belong.

Those native to the Appalachian region often become what might be called bilingual. This means that they still speak in English, but use different dialects when talking with colleagues, family, or persons encountered in medical settings. You must be able to speak the language of your profession when you are with your colleagues. However, you must also retain and use the language of your family and community when talking with others. If you use professional language or medical terms, some people may not understand what you mean. Thus, you must consider if the message is heard and understood. If you try to use professional language around family, they may see you as acting uppity or trying to impress someone. It is always important to be conscious of what is being communicated.

One other thing to consider is written communication. This is important when we

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**Communication is the Key!**

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write letters or memos to others. It is helpful to have others look over your documents to ensure that your work is error-free. Another thing to consider is what some call netiquette, or the appropriate way to communicate online with others. Many useful internet resources are available to help with this form of communication.

**List 3 Communication Topics You Think Important to Discuss with Volunteers:**

**Work with Teams**
A team can be defined as a group of people who share a purpose and some ideas. Addressing diabetes in your community requires a team effort. In health care, we often think about teams where physicians, nurses, dieticians, physical therapists, and others work together. When it comes to diabetes, teams may also include specialists such as pharmacists, endocrinologists, ophthalmologists, and podiatrists. Other care providers could include occupational therapists, psychologists, or psychiatrists. A medical supply company, a home health agencies, or meals-on-wheels may be represented on teams. A community-based diabetes team needs the support of potential members. Getting local health professionals involved with your Diabetes: A Family Matter program will strengthen your work.

**Work with Community**
Everyone may not be interested in participating, but community residents and groups need to be informed and invited to take part in events and activities sponsored by your local Diabetes: A Family Matter program. It is important to keep welcoming the community as a whole and finding new ways to reach out. Think about ways to involve individuals and groups in your efforts. Involvement is things like giving time, money, effort, attending an event, or telling others about the program. Think creatively! The more widely you reach into the community, the greater the potential for program success.

**Work with SUGAR Helpers**
You will recruit a cohort of volunteer SUGAR Helpers, a KEY part of the project team. Next, you will provide them with education and training. After the training is completed, you will need to provide ongoing support, monitor their activities, and keep pertinent records related to their activities for annual reports. After SUGAR Helpers are prepared and engaging in community work, additional cohorts can be recruited. Using regular support sessions, you will find ways to integrate new SUGAR Helpers into the larger group and community activities.
5

DIABETES: A FAMILY MATTER TOOLKIT

» Using the Toolkit
» Toolkit Materials and Toolkit Activities
» Ways to Use the Toolkit
» Ways Community People Use the Toolkit
» Ways Health Professionals Use the Toolkit
» The Diabetes: A Family Matter Website
» Family and Community-Focused Materials
» The SUGAR Helper Manual
» The Film: Living with Diabetes in Appalachia
» The SUGAR Plays
» Fotonovellas: Family Support versus Non-Support
» Family-Focused Brochures
» Diabetes: A Family Matter Posters
» Media Campaign
» Ice-Breakers
Helping people reduce diabetes risks and live healthier lives is the primary goal of this program. Tools and materials designed for the toolkit and website have been created with family and community as the focus.

**Using the Toolkit**

This manual is only part of what is available for the *Diabetes: A Family Matter* program. Other materials are available online. Take some time to review all of the resources. This manual provides some ideas that can help you begin a program and sustain it over time. By tailoring this program to your community, materials can be adapted for best use. The toolkit materials and activities can be implemented in many different ways. The best way is the one that works where you live. Hopefully, you will share what works for your group with others via the website and also learn things from what others have tried.

The program website: [www.diabetesfamily.net](http://www.diabetesfamily.net) contains information and items for use by persons with diabetes, their families, diabetes or health educators, health professionals, and others in the local community. These materials are copyrighted by Ohio University and owned by Ohio University and Sharon A. Denham. Permission must be obtained for any commercial use. However, communities in the Appalachian region can make free use locally of information and resources found here.

**Aims of the Diabetes: A Family Matter Toolkit:**

- Provide tools to help communities increase the visibility of diabetes locally.
- Suggest ways to increase awareness about diabetes prevention.
- Identify ways persons with diabetes and family members can better manage the disease.
- Empower persons, families, and groups to engage in healthy behaviors.

Take a look at the website to find what is useful for you and your community. On the program’s website, you will find five main sections on the front page. Take some time to look these over and see all that is there. As a volunteer SUGAR Helper, you might find that the **Toolkit** and **Communicate** sections will be of great interest. In the Toolkit section, you will find the **Toolkit Materials** and the **Toolkit Activities**. These are described in greater detail below. Prior to downloading materials from the website, you will need to register online. Information obtained will be used to identify where materials are being used or distributed, but will not be shared with commercial enterprises.

**Main Sections of the Diabetes: A Family Matter Website:**
- Family
- Community
- Toolkit
- Programs
- Communicate

*Diabetes: A Family Matter* is not a medical organization. The information and reports available here should not be substituted for medical advice or treatment. Some information may not be suitable for all people. Be sure to urge volunteers and others to caution those with diabetes to seek the advice of their doctor before changing any activity patterns, medical
treatment, medicines, or diet. This site is not associated with any commercial product or business and does not support the use of a specific drug, medical or food product or companies, or diet plan.

**Toolkit Materials and Toolkit Activities**

Many excellent resources already exist for diabetes prevention and diabetes self-management. At the *Diabetes: A Family Matter* website, you can find some easily accessible links to excellent education materials. The information developed by the government (e.g., Centers for Disease Control and Prevention, National Diabetes Education Program) and other organizations (e.g., American Diabetes Association) will provide you evidence about best practices related to diabetes, prevention, and management. However, few existing diabetes materials are available specifically for family and community use. While anyone may use the *Diabetes: A Family Matter* toolkit, it has been especially crafted for those living in the Appalachian region.

This toolkit moves away from using an exclusive medical model and traditional forms of diabetes education. Instead, the Family Health Model (Denham, 2003) was used to develop the toolkit and design materials where diabetes and diabetes prevention and care needs are viewed from family perspectives. Rather than merely focus on the person with diabetes, the toolkit suggests ways to think about relationships among diabetes, health, persons with diabetes, their family members, and communities. When it comes to diabetes care, educators generally believe that family and community are important, but education programs and teaching materials seldom focus on these systems. This toolkit addresses some gaps visible in the materials currently available. For example, people living in rural areas may have some different ideas and concerns than those living in more urban areas. Thus, the photos and text of the materials is targeted for those who are more likely to be living in or linked to these areas of Appalachia.

**The Family Health Model Focuses on Three Areas:**

- The complexities and links between family household, community, and developmental paths of family members.
- The ways family members interact within and outside of the family.
- The routines and rituals of daily life.

Many diabetes and health education materials for use with health professionals, volunteers, and community persons are available through this website. If you have not already done so, go to the *Diabetes: A Family Matter* website and look around. You will find many types of information about diabetes, families, and community. You will also find a section of the website called Toolkit. Here, you will find many Toolkit Materials and Toolkit Activities for use in your community.

The materials and activities can be used by SUGAR Helpers as they talk with individuals, families, and groups in local communities. For example, the brochures could be shared with individuals and their family members. Volunteers might want to begin with their own families. The brochures could also be shared with family members or friends of persons with diabetes. While these could be used in a medical office, they can also be shared with people in the community or other groups where you are a member. During the volunteer training sessions, take some time to brainstorm with the volunteers about different ways to use the Toolkit Materials and Toolkit Activities.
Some Things Included in the Toolkit Materials:

- Diabetes Educator Manual
- SUGAR Helpers Manual
- Film: Living with Diabetes in the Appalachian Region and Discussion Guide
- Series of Brochures about Diabetes for Family Use
- Series of Posters about Diabetes and Family
- Fotonovellas (two photo story booklets that describe the negative and positive things that can happen in a family when support is or is not available to the family member diagnosed with diabetes)
- SUGAR Plays (three 20-25 minute plays about living with diabetes in Appalachia) and Discussion Guides

The Toolkit Materials are copyrighted, but they can be freely used for education or community use. These materials may not be used for commercial purposes. When you use them, be sure to mention the Diabetes: A Family Matter program and tell other people you meet about the website. You can make copies of these items for yourself or to share with others. Your local volunteer group may choose to use some materials in community-wide programs.

Ways to Use the Toolkit

Volunteer SUGAR Helpers and others will use the online Toolkit Activities to obtain ideas for community projects. Toolkit Activities and resources can be shared with individuals, families, and groups. Some of these materials and activities should be reviewed during the SUGAR Helper educational program. You may want to choose several examples of materials and activities and brainstorm with the volunteers about different ways they might be used.

Some Things Included in the Toolkit Activities:

- Activities to be Used with Individuals, Families, Groups, and Communities
- Media Campaign Materials
- Ice-Breakers

During your educational sessions, you may want to identify some specific independent volunteer activities to be completed during the training period. By the end of the sessions, you may want to have selected a group activity or event to work on together. Over time, you will add new ideas and activities. It could be beneficial to focus on specific events or activities throughout the year. Choose the best ways to use the toolkit materials and activities in your community. With experience, SUGAR Helpers will develop the expertise to point community individuals, families, and groups to online activities as well.

Ways Community People Use the Toolkit

On the Communicate section of the Diabetes: A Family Matter website you will find a social networking site. On this site, you can meet other program leaders and health professionals working to create healthier communities and prevent diabetes. The program volunteers can talk to other SUGAR Helpers online and meet others with diabetes and family members from the Appalachian region. The purpose of this social networking site is to make living with sugar diabetes more visible and help local people get the facts they need to live healthy lives and prevent the spread of diabetes and its complications.

The social network site in the Communicate section is intended for persons living with
diabetes in the Appalachian region to meet and talk to one another. Those who have or are at risk for diabetes can talk about the problems of living with the disease. They can talk about what they do to overcome the problems! Family and friends can join the conversation! Diabetes educators and other health professionals can share information and ideas as well. Currently, there is not a website focused on diabetes just for those in Appalachia. This website can provide ways for those who have fewer local ways to find the help or information they need to connect with others that might help. Talking about living with diabetes can be important steps in prevention and self-management.

As people across Appalachia use these program materials, it is hoped that they will share what they are doing. Those that begin Diabetes: A Family Matter programs throughout Appalachia or use the Toolkit Materials are invited to discuss them on this site. Please share ideas about things you have done in your community. What kinds of things are you doing to help prevent diabetes and its risks? What kinds of things are you doing to help people better manage diabetes? How are you getting local families and groups to aim for healthy lifestyles? Which materials or activities have you used? How did they work? As people share their ideas, this website will become more interesting and useful over time to enrich the website.

While others might also access and use the toolkit resources, they have been primarily targeted for those that live in Appalachia. Persons with diabetes and their families can use some online resources by themselves. They will have access to the social networking site. At this website, persons living with diabetes, family members, friends, and others can share the successes and challenges of diabetes. The purpose of this site is to make diabetes more visible in the Appalachian region and provide a way for people to share with one another. People living in rural areas do not always face the same problems as those living in cities and the distance between our residences may make this type of communication even more important.

The Online Social Networking Site:
- Connect with others in the Appalachian region living with diabetes.
- Talk about living with diabetes with others in Appalachia.
- Share what works well to prevent and manage diabetes.
- Discuss ways to live healthier lives.
- Talk about resources that can help overcome barriers.

List 2 or 3 Ways You Think Local Persons with Diabetes and their Families Can Use this Website:

Ways Health Professionals Use the Toolkit
Health professionals that live and work in the Appalachian region may find many of the materials on the Diabetes: A Family Matter website (www.diabetesfamily.net) useful. Resources about diabetes management related to schools, workplace, and other community concerns are located here. Web links to informational resources about family care and topics pertinent to professional diabetes
education are available. The website can help community members and health professionals learn ideas about ways to promote healthy lifestyles, diabetes prevention, and diabetes management.

**The Diabetes: A Family Matter Website**

The website contains items that can be accessed by local communities. All materials are available free of charge. In addition to the toolkit materials, other resources are available about diabetes, Appalachia, family, and community.

The materials and activities available can be used to develop your local program. In order to download the materials from the website, you will need to register online. This information will be used to identify who is using the program. It will also help us know where in Appalachia things are being used. Programs using the materials will be asked to share ideas with others. Thus, a community exchange of ideas will occur and hopefully become more valuable over time as groups share their new ideas. This will help us know more about good ways to do things with the materials. This program can grow as people from all over the Appalachian region share their ideas with one another.

### List 3 or 4 Ways You Think the Website Might Help You In Developing a Local Program:

#### Family and Community-Focused Materials

Helping people reduce diabetes risks and live healthier lives is the primary goal of this program. Tools and materials designed for the toolkit and website have been created with family and community as the focus. While diabetes may be a disease that happens to individuals, the disease is experienced in family households and community places. The kinds of support needed to prevent and manage diabetes are linked to healthy lifestyles. Connecting health needs to caring community persons that support family management is an important step in reducing diabetes risks and promoting care management across many households.

#### The SUGAR Helper Manual

The SUGAR Helper manual provides information about the roles and activities volunteers play in a community *Diabetes: A Family Matter* program. The manual can be downloaded from the program website and is intended for use during your educational training program. The manual discusses record and other keeping activities of volunteers. This manual can be used along with the toolkit materials and activities.

#### The Film: Living with Diabetes in Appalachia

A film entitled *Living with Diabetes in Appalachia* is viewable online. The film is accompanied by a discussion guide that can be printed. Diabetes educators, SUGAR Helpers, and others can show this film to persons with diabetes, families, and community groups. The purpose of this film is to encourage local conversations about diabetes in the community.

People rarely talk with one another about diabetes. Persons with diabetes and their family members seldom have conversations about the disease and the ways it affects their daily lives. Church and other groups often have
many members with diabetes, but may give little attention to the ways they might provide support.

Directed by Dr. Sharon Denham and produced by Steve Fetsch, this film is a window into the lives of several families living with diabetes in the Appalachian region. Through the film, persons with diabetes and family members share some of the successes and challenges faced in managing diabetes in their homes and communities. The discussion guide promotes the opportunity to have a “talk-back session” after viewing the film. This film can be used at a support group meeting, a diabetes education session, or a fund-raising event. Showing the film to a church group, a civic organization, a class, or any community group is a way to talk about how to make diabetes more visible.

The SUGAR Plays

Getting messages out about diabetes can occur in a variety of ways. Three theater students at Ohio University were commissioned during the 2007-2008 academic year to write plays about living with diabetes in Appalachia. Each writer was asked to develop a play that lasted approximately 20 minutes and included five characters or less. Each playwright did research about Appalachia and diabetes as they learned firsthand about the region and its implications for living with diabetes. Three diverse and remarkable plays were written.

The plays can be viewed on the Diabetes: A Family Matter website and the three files containing the play scripts can be downloaded. A companion discussion guide to use in a “talk-back session” after viewing the plays is provided. The playwrights have given permission for the use of the plays locally for diabetes work. These plays are copyrighted by the playwrights and any other use of the plays will require permission from them.

The SUGAR Plays:
- Sugar Bear by Dana Lynn Formby
- A Family History by Nick Sgouros
- Lucille by G. William Zorn

The plays may be used in different ways in your community. The accompanying discussion guide provides a way to have a talk-back session after each play to engage the audience. The plays may be read individually at support meetings where participants assume various roles followed by a group discussion. Used at consecutive monthly support meetings, these plays could be a good way to think about diabetes from a variety of perspectives. Whoever leads sessions such as these will want to read all three plays and think about how they might want to utilize them. The three plays could also be staged at a community venue to increase awareness or as a way to raise funds locally for your diabetes project.

Fotonovellas: Family Support versus Non-Support

A fotonovella is a Spanish word that means photo story. A fotonovella presents information about a disease or illness in an engaging way that is interesting to the reader. It is also a good way to address problems of low literacy or low health literacy. By using small amounts of text and pictures, a story can be told that presents ideas in a realistic way that is easy to understand. These fotonovellas address diabetes care needs from a family-focused perspective.

Two fotonovellas have been created as part of this toolkit and are available for use in communities. One is entitled Living with Sugar Diabetes. The story of this fotonovella is about a woman who is diagnosed with diabetes, but her family does not give her the support she needs to cope with her new diagnosis of diabetes.
second fotonovella is entitled *Family Support for those with Sugar Diabetes*. This second story provides a more positive view of what can happen when a family offers valued support to a family member diagnosed with diabetes.

Files for these fotonovellas are available on the *Diabetes: A Family Matter* website (www.diabetesfamily.net) and can be used with your diabetes education classes, support groups, and other education. A discussion guide is also available online and can be used after the fotonovellas are read. Fotonovellas can be placed in a variety of public places where they might be readily accessed. Places such as beauty parlors, barber shops, laundromats, car washes, automotive repair shops, or other places where people have to wait for services can be good places to make these available. Be creative and find ways you can use these materials in your program and community.

**Helping people reduce diabetes risks and live healthier lives is the primary goal of this program.**

**Family-Focused Brochures**

A series of nine brochures has been created for use in highlighting improved health outcomes for individuals, families, and communities. They focus on healthy living, diabetes prevention, and diabetes self-management. Written with attention to cultural needs, these brochures are illustrated with photos of people living with diabetes in Appalachia. They have been crafted to share small bits of pertinent information in an easily read format sensitive to all reading levels. While sections of the brochures vary on reading levels, most aspects are between sixth and ninth grade levels.

**Brochures aimed at Diabetes Prevention**

- What You and Your Family Need to Know about Diabetes
- It Takes a Village
- Talk to Your Kids

**Brochures aimed at Diabetes Self-Management**

- Healthy Living: Family Routines Count
- Your Family’s Genes Count
- When it Gets Complicated
- Sharing Healthy Family Routines
- Depression and Diabetes
- The Balancing Act

These brochures can be used as educational pieces about the specific topics. They can serve as discussion topics for a series of support group sessions. The brochures could be used in physician offices as tools to assist patients with diabetes and their family members better manage their lives. The three prevention brochures could be widely distributed to groups in the community to increase local awareness about diabetes and what can be done to prevent it. People in your community program can decide the best ways to share these brochures. They can be viewed and downloaded from the website.

**Diabetes: A Family Matter Posters**

The posters use the same themes as the family-focused messages. These colorful posters can be found on the online website and downloaded. The posters can be used locally to increase the awareness about diabetes and prevention. You might want to use them as part of a local campaign, event, or activity. You may need a special printer that can print with color ink for these posters.
Conduct a Media Campaign
A critical step in developing a successful program is being able to provide community people with messages that garner their attention. People in rural areas may have fewer resources available to develop expensive advertisements for local newspapers or place them on the radio or local television. On the Diabetes: A Family Matter website, aids to construct media message for the newspaper, radio, or television can be found.

Ice-Breakers
Ice-Breakers are brief activities to help small or large groups get acquainted. These activities can also be useful to assist people to get acquainted and discuss topics that are less comfortable. Icebreakers are good ways to open sessions and get groups discussing important ideas. They keep everyone involved and help them to feel more comfortable. Using icebreakers can be a great way to liven up a group. Examples are provided at the online program website. An ice-breaker is provided for use with each of the six volunteer SUGAR Helper training sessions. Additionally, volunteers can use these activities as they work in their communities.

Take advantage of other ideas that may be available through the internet, the library, or ones that you might obtain in some other way.

Adapt ideas you might be familiar with to include a health or wellness focus and learn more about diabetes prevention and management.
THE SUGAR HELPERS’ EDUCATIONAL SESSIONS

» Develop the SUGAR Helper Team
» Schedule the Diabetes Education Program
» Review the SUGAR Helper Manual
» Educational Training Sessions
» Goal Setting
» Spotlight on the Family
» Spotlight on the Community
» Understand Local Needs
» Be Creative
Develop the SUGAR Helper Team

As previously discussed, volunteer selection is an important and critical step to success. It is essential to choose your volunteers wisely and prepare them adequately to do the needed tasks. New volunteer SUGAR Helpers will likely be unsure of their abilities and might be nervous at first. They will need to gain confidence and learn needed skills. Not only will you need to train them about diabetes risks and management, but they will need to gain skills for interacting with the larger community.

Schedule the Diabetes Education Program

Set the dates for your SUGAR Helpers volunteer training program. As mentioned earlier, it is suggested that you consider planning a six session educational program with each session lasting about two hours. You want the program to be long enough to include all of the necessary topics and help the SUGAR Helpers gain self-assurance.

Positively Model Behaviors for Volunteer SUGAR Helpers:

- Be on time and prepared when meetings are scheduled; their time is important.
- Assist volunteers to get acquainted.
- Show enthusiasm during meetings.
- Describe things simply and clearly and be sure they understand important ideas.
- Demonstrate that you value healthy living and diabetes prevention.
- Exhibit positive interactions with others related to health behaviors.

Review the SUGAR Helper Manual

A SUGAR Helper Manual is part of the toolkit available on the Diabetes: A Family Matter website. Take a look. Print a copy so that you can review it. The SUGAR Helper Manual is intended to be used during the volunteer’s educational training sessions. Think of this manual as a resource book that volunteers can take with them as they learn more about healthy living, diabetes prevention, and diabetes self-management. The manual includes ideas for community projects, activities, and events. Each volunteer SUGAR Helper will need a copy for their use when attending the educational sessions.

Educational Training Sessions

Training sessions are intended to prepare SUGAR Helpers in effective ways to communicate with individuals, families, and community groups. Because the Sugar Helper program is flexible, you will decide what is included in each of the sessions. Materials included in the Diabetes: A Family Matter toolkit such as the series of nine family-focused brochures, the film Living with Diabetes in Appalachia, the fotonovellas, the three plays, and the toolkit activities are resources that can be used in the educational sessions. Creating activities that use these materials and tools can help volunteers learn about the available materials and suggest ways to use them with persons with diabetes, families, and community groups.

As the local expert, it is up to you to decide the content volunteers need for work in your community. Take time to consider different options. You may want to use materials that expand your knowledge about healthy living, diabetes prevention, and care. After you have reviewed resources and identified the content to include, next develop an agenda for the educational training sessions. Identify the topics, content, and activities to cover at each session and estimate the time needed for topics. APPENDIX E provides a suggested outline to consider when planning your educational sessions.

It might be helpful to use icebreakers in your
training sessions. These activities encourage volunteers to share information and get to know one another were described earlier. A few ice-breakers to use at your educational sessions can be found on the Diabetes: A Family Matter website.

**Topics to Include in the Educational Sessions:**
- Get acquainted activities.
- General education about all forms of diabetes.
- Ideas about culture and diversity.
- Communication with individuals, families, and groups.
- Discuss empowerment.
- Information about wellness and healthy lifestyles.
- Facts about diabetes prevention and diabetes self-management.
- Ideas about ways to use the Toolkit Materials and Activities.
- Ways volunteers can get involved in the community.
- Personal goal setting.
- Record keeping activities.

**SUGAR Helper Educational Sessions:**
List 3 or 4 Key Topics You Think Important to Include in the Training Sessions:

**Goal Setting**
Earlier in this manual, program goals were discussed. A second type of goal important for this program is personal goals, the ones individuals set for themselves. Individuals usually set goals different from one another. During the educational sessions, the volunteer SUGAR Helpers should be asked to set a single personal goal to achieve during the course of the training program. This goal should be related to a health promoting activity.

**Identify a Personal Health Goal You want to Achieve, One You Can Model for Volunteers:**

When setting a goal, it is important to be specific about what is to be accomplished. In order to meet a goal, an action plan is used. An action plan states exactly what the behavior will be, where it will take place, how often it will be done, the length of time involved, and degree of confidence you have that it will be accomplished. If a scale of 1 to 10 is used and 10 is the greatest amount of confidence that a goal might be accomplished, then persons should choose an activity that they have at least a “7” level of confidence. If the level is lower, then the likelihood of meeting the goal can be significantly decreased. Everyone should be encouraged to choose a goal that is viewed as achievable. Having
confidence in the ability to achieve a goal is also called ‘self-efficacy.’ Self-efficacy was one of the things mentioned earlier in the manual.

Personal goals are also about what each volunteer hopes to achieve in the year ahead. Setting a time limit helps volunteers examine what they have done. The goals might pertain to the amount of time spent involved in the project, the program activities that will be completed, places where you will reach out in the community, and personal expectations. Personal health goals should be discussed at the first educational session. Each volunteer should work on shorter term goals that are related to personal health.

At the end of educational sessions, each volunteer should set at least 2 or 3 personal goals for the year (APPENDIX F). These goals should pertain to what is aimed for in the year ahead. Assist volunteers as they set their goals to assure they are important to them and achievable. Make copies of their goal sheets to retain for your records. Suggest that they place their copy where they can view it regularly. Remember to revisit these goals at your monthly support meetings. Let the group do some brainstorming and problem solving to assist those that have difficulty achieving their goals. It is likely that some volunteers will achieve the personal goals they set before the end of a year. In that case, they might want to set new ones. Accomplishment of personal goals should be evaluated at the end of the year.

Examples of Long Term Personal Goals:
- Spend three hours weekly in volunteer work (Specify what you will do).
- Develop a women’s group at a local church that focuses on healthy behaviors.
- Increase my activity to include walking 20-25 minutes each day 4 days a week.
- Attend monthly support meetings with other SUGAR Helpers.

Spotlight on the Family
Management of diabetes mostly takes place at home. Family can be great supports for persons with diabetes. However, families do not always know the facts! Sometimes, what they know about the disease has changed. Many families have had other members with diabetes and can only think of the bad things that happened to them in the past. Some families might think that there is little they can do to manage diabetes; they feel that negative outcomes are inevitable. Other families just ignore the diabetes. They think it is not their problem! Still other families try to control or police every action of the person with diabetes and wind up trying to help by nagging all of the time.

Families need the facts about how to live with sugar diabetes. They need to know how to manage Diabetes and day-to-day problems.

Sometimes people that are diagnosed with diabetes feel like failures! They might think the disease is their entire fault. Persons often feel guilty for letting it happen and blame themselves for not taking better care. When the person with diabetes is a woman, she may not take good care of herself because her health needs interfere with what her family wants. Family members often have conflict with one another when diabetes enters their homes. Different generations may have different needs as they live with diabetes.

Families need the facts about how to live with sugar diabetes. They need to know what is most important when managing the disease and how to handle day-to-day problems. Many people new to diabetes have not attended a diabetes education class. Or, if they have received some education
in the past, it may be outdated. Things have changed! Diabetes is managed differently than it was years ago, but families may not understand. Families need to know what has changed and learn the best way to live with diabetes at home, work, and play.

SUGAR Helpers can assist individuals and families to learn the facts about sugar diabetes. As they are educated about diabetes, it will be important to stress the important roles that families play in diabetes self-management. Use of the Diabetes: A Family Matter brochures, film, plays, and other materials will provide tools to talk with families about diabetes care.

**Family and Diabetes Care**

Identify 3 or 4 Ideas about The Roles of Family in Diabetes Self-Management

Important to Teach Volunteers:

- Learn more about diabetes.
- Attend diabetes education classes.
- Learn how to handle medical emergencies like low blood sugar.
- Set an example by eating healthy foods.
- Join in exercise programs.
- Provide rides to and sit in on doctor’s appointments when appropriate.

- Shop for healthy foods for the house.
- Try new fruits and vegetables.
- Watch their portion size along with their family member.
- Provide emotional support as needed.

**Ideas to Get Families Involved in Diabetes Care:**

- Invite families to attend diabetes awareness events.
- Hold diabetes cooking classes for family members.
- Organize diabetes fundraisers that emphasize family involvement.
- Educate family members about their risk of developing diabetes.

**Spotlight on the Community**

It is important not to leave community out of your plans. Teaching individuals only about self-management will be a slow way to get the news out about healthy living, prevention, and good self-management. A key part of the challenge is to think about ways people can become more aware of diabetes and ways to prevent it. Creating ways for volunteer SUGAR Helpers to participate in the community is an essential part of the Diabetes: A Family Matter program.

**Ways to Involve Local People in Diabetes Care:**

- Ask business people to display diabetes information.
- Promote healthy menu choices at restaurants in town.
- Organize Be Active programs.
- Encourage churches to provide space for diabetes support groups.
- Talk to school teachers and administrators about healthy foods and physical activity for students.
- Involve local scout troops and 4-H programs.
Print a diabetes newsletter and include local news.
Stage a diabetes health fair.
Sponsor an event to raise money for local people that need diabetes education or supplies.

List 3 or 4 Ways You Think Will Be Good to Involve Local People in Health and Diabetes Activities:

Understand Local Needs
Every community is different! While it is true that communities have similarities, they also have distinct and unique qualities. Trying to initiate a program that does not capture local interest is useless work. If you are not familiar with the community outside your workplace or coalition, take some time to get acquainted. Learn what community people like and do not like. Discover what kinds of ideas are likely to be accepted by others and what are not. Find out what kinds of things have been successfully done in the past and use these things as models for your Diabetes: A Family Matter project.

Include the “movers and shakers” of your community. These are the people that energize things with fresh ideas and get things done. Include them on your team! Identify the “opinion leaders” or the people who are likely to sway others into thinking one way or another. Be sure to speak with them and find out what they think, share your ideas with them, and see what they suggest. Talk to the local leaders and key health professionals that are critical to include as part of your efforts. Most importantly, listen to the individuals and family members who contend with diabetes on a daily basis. What do they tell you they need?

A successful community program must be built into a partnership with community people. It is better to build a strong support team at the beginning than to try to repair problems at a later date. The time you spend initially in learning about the community and its people will help you build the foundation needed for a strong program.

Be Creative
Keep in mind that the Diabetes: A Family Matter program that you create in your community belongs to YOU. This manual is here to give you ideas to begin your work and develop the program. However, the program you develop belongs to you and your community. Use your understanding about the community and let your imagination help you develop a unique program specific to your location and community citizens. Think of new ways to present health and prevention messages in your community. Get people involved! The more people engaged in different aspects of your activities, the greater your chances for success.

List 3 or 4 Creative Things You Will Include in Your Program:

The SUGAR Helpers’ Educational Sessions
RETAIN VOLUNTEER SUGAR HELPERS

» Welcome a New Cohort of SUGAR Helpers
» Offer Support
» Length of Commitment
» Give Recognition
» Keep Things Fresh
» Keep Current with Other Resources
Volunteer SUGAR Helpers that understand about healthy living and diabetes can spread important information everywhere they go. Your community can become more knowledgeable about these things as you provide education and support to your volunteers.

Recruit New SUGAR Helpers

It is important to recruit new volunteers on an annual basis to sustain the diabetes community program. You should have a plan for when and how you will recruit new volunteers into your program. In some communities, annual recruitment will be enough. If your community is larger and you have the resources, you might plan to recruit new volunteer cohorts twice a year. Regardless of what you plan, retaining seasoned volunteers and reaching out to include new ones will help keep your program vital and further your reach into the community.

Continued Recruitment of New Volunteer SUGAR Helpers:
- Mention needs for volunteers at events organized by the program.
- State that new volunteers are always welcome every time you advertise the diabetes community programs and activities.
- Discuss the benefits of being a volunteer (e.g., training, new friends, helping others, community involvement, etc.).
- Promote the successes of the program and the roles volunteers play.
- Encourage current and past volunteers to network to find additional volunteers.
- Ask active volunteers to assist you in recruiting new volunteers.
- List things that volunteers do—one for individuals and one for the community.

People enjoy volunteering. Work to promote your program as a great place to volunteer! Word-of-mouth is the most important means of volunteer recruitment. If volunteers view their activities in positive ways, they will talk with others and encourage them to get involved.

List 2 or 3 Things You want to Discuss in Volunteer Recruitment:

Offer Support

Provide a way for volunteer SUGAR Helpers to contact you if needed. You do not have to be continually available, but volunteers appreciate being included and able to talk with those who lead programs. Find ways to be actively involved in some projects and activities where you can directly interact with volunteers. Know volunteers by name and be aware of what their individual efforts are in your program. Volunteers that believe they are treated respectfully and their work valued will want to continue.

Check in with volunteers on a regular basis to make sure there are not problems or concerns. Providing a way that you can get regular feedback from volunteers is important. Put a Suggestion Box in a visible place. Some volunteers may not be comfortable telling you what they think by sharing their concerns in person. The use of a Suggestion Box allows volunteers to be anonymous and still give you feedback. Be sure to make the Suggestion Box available at support meetings. Emphasize how
important their input is and try to publicly respond to messages that have been left. You might want to review these ahead of time so that you can be prepared. Encourage everyone to add suggestions.

Having regular support meetings with your SUGAR Helper volunteers is important. Given that you want them to spend most of their time in the community; you may want to consider how often you want to meet. A meeting once a month is likely to be often enough to keep them involved and connected. Meetings can encourage motivation for your program. However, if you meet too often, it can be a burden. Talk with the volunteers and get their input! What will work best for them?

Have a plan for what you will do at support meetings! As part of the support meetings, continuing education on healthy lives and diabetes management will be useful. By keeping them updated and helping them grow stronger in their understanding of diabetes, you will help them more easily share information with others.

Volunteers need to sense that these meetings are a good use of their time. You may want to use these meetings to plan and work on activities together. If volunteers are doing independent community activities, they can share their experiences with others during this time. They can describe what has or has not worked as they use toolkit materials. Allowing volunteers to have control over the activities they want to do together and individually will be empowering.

**Ideas to Consider for Support Sessions:**

- Create open meetings with icebreakers to help volunteers relax and talk.
- Have an agenda that is well-planned yet flexible.
- Share personal experiences of what each volunteer is doing.
- Highlight a volunteer each month, letting the group become more acquainted with them, and recognizing what they have accomplished.

**Identify 3 or 4 Things You want to be Part of Volunteer Support Sessions:**

**Length of Commitment**

No one wants to join anything as a volunteer forever. It is important to allow for community members to commit for a time period. Invite volunteers to think about a year commitment. Make it clear that this can be extended as many times as they like. Also, let them know that it is fine if they want to ‘retire’ at the end of the year and are welcome to return at a later time. Giving people a way to both begin and end a volunteer experience will strengthen their willingness to be involved.

**Give Recognition**

People appreciate being recognized for the work that they do. Although volunteering is something many people enjoy, it becomes even more satisfactory when they know that others see their efforts and value their worth. You may want to plan an annual event where SUGAR
HELPING VOLUNTEER SUGAR HELPERS

Allowing volunteers to have control over the activities they want to do together and individually will be empowering.

Helper volunteers, your coalition members, and advisory group are recognized. Creating a series of awards that can be given to volunteers for their efforts and celebrating the successes of your program are important. Such events can draw media attention and suggest ways to keep telling the Diabetes: A Family Matter story in the community.

You may want to keep written records about the dates volunteers commit to service. This will allow you to track the time they give to the program and identify their activities. Keeping a file on volunteers with their hiring and individual activity records can be a way to track these efforts. At the end of each year of service, you may choose to send a letter of thanks for the time they have volunteered, the work they have done in the community, and the particular contributions they have made.

Recognize Volunteers:
- Pay attention to volunteers by knowing their names and treating them with respect.
- Leave notes of appreciation with a small candy or treat.
- Host an annual or semi-annual potluck.
- Relay positive feedback received from the community.
- Provide a letter of reference noting volunteer efforts.
- Write letters of appreciation to a volunteer’s employer.
- Write a letter to the newspaper editor and describe what Sugar Helpers are doing in your community.
- Say “thank you” often.

Identify 3 or 4 Ideas You want to Include in Ways Volunteer Recognition is Addressed in Your Program:

Keeping your volunteers motivated can be one of the toughest challenges. Learning what motivates your SUGAR Helpers is important. Why did they choose to become a SUGAR Helper? You may want to ask this when they apply or at the first educational setting as part of an icebreaker activity. Ask volunteers to write this down and then collect the information. Keep a record of their personal goals that you ask them to write at the end of the educational sessions. As the year goes by, check in to see if they are doing the things they said they wanted to do. Check in with them individually to see if they are happy with their experience. Assist them to be engaged in activities they find personally satisfying.

Volunteers tend to be altruistic, that is they often desire to help others and make contributions to the lives of others. Some may view their volunteer activities as a means of
service, a way to meet new people, or connect with the community. Being a volunteer SUGAR Helper should produce a positive response in volunteers’ perceptions. Most volunteers need to feel appreciated and accepted. Some volunteers may get involved as a way to strengthen their resume. Others might choose involvement because they have retired, but want to stay connected socially. Whatever the motivation, it is important to help volunteers find the type of work or activities that best meets their needs.

**When Planning Volunteer Activities:**
- Choose at least one featured activity that the group will work on together annually and cooperate to promote as a community event.
- Encourage smaller group activities where several volunteers work together on smaller projects that occur throughout the year.
- Support individual volunteers to identify and complete activities they can conduct independently with their own family, other community families, and groups where they belong.
- Find a balance between regular programs, events, or activities and trying to add some new ones.

**Keep Current with Other Resources**

The science and art of diabetes care has changed rapidly. As new medical discoveries are made, the ways people manage diabetes changes also. It is important to stay current with these changes in medical management. Keep in mind that as new things are found, persons living with diabetes and their families also need these updates. Use the links on the *Diabetes: A Family Matter* website to find recent information about diabetes care management.

As a diabetes educator, it is important to read journal articles and research reports so you can be familiar with the evidence about best practices in diabetes management. It is a good idea to read at least one journal that focuses on diabetes regularly. Reviewing materials and information at government and diabetes websites can also help keep you current. Attending national, state, and regional conferences about diabetes care are valuable ways to get updates and develop networks of colleagues that share your interests. You are an important part of the diabetes care team and many will depend on you to share new information and keep them informed. Conferences can be expensive to attend. As the diabetes educator, you might get a community partner to help fund your travel to one state or national conference each year. An important thing to do when you return is to report what you learned at the conference; particularly if someone else funds your travel.

**Being a volunteer SUGAR Helper should produce a positive response in volunteers’ perceptions. Most volunteers need to feel appreciated and accepted.**

It is not unusual for persons with diabetes to have attended a diabetes education session soon after the diagnosis is made. However, some persons have never had a formal diabetes education class and neither have their family members. Volunteer SUGAR Helpers that understand about healthy living and diabetes can spread important information everywhere they go whether it is in formal or informal situations. Your community can become more knowledgeable about these things as you provide education and support to your volunteers. Keep in mind, SUGAR Helpers will reach many people that health professionals will never see. Volunteers are important in changing the health of your communities.
Keep Current
List 2 or 3 Ways You Plan to Stay Current with Your Personal Health and Diabetes Knowledge:

See the Toolkit Materials online to find posters and a flyer that can be used for volunteer recruitment. You can also find some media campaign materials to assist with advertisement.
SUSTAIN YOUR PROGRAMS ACTIVITIES

» Keep Your Program Going Over Time
» Annual Reviews
» Community Goals
» Making a Difference
» Record of Personal SUGAR Helper Goals
» Keep Records
» Write Reports
» Keep the Community Informed
Keep Your Program Going Over Time

Sustainability of your program is an issue of concern. To assure that your program continues over time, several things need to be considered. First, a dedicated leader is essential. Second, a group of supportive community leaders or a team of like-minded persons is necessary. Third, clear goals for what you intend to accomplish are essential. It is important to know where you are going and how you plan to get there! Fourth, it is important to be prepared to do the work you set out before you. This will likely include time, resources, and finances. Next, you must have a well-prepared and active group of SUGAR Helpers. These are the “worker bees” of your program. They are the ones that help you accomplish great things in the community and make doing it fun and satisfying. Finally, you must have a way to review your accomplishments and measure your outcomes.

Ways to Keep Your Program Going Over Time

- Have a dedicated leader.
- Find a supportive team.
- Establish clear goals.
- Get ready to take action.
- Evaluate time, talents, money, and other resources.
- Select and train SUGAR Helpers.
- Review your accomplishments at least once a year.

Important Uses of Annual Reviews:

- Disclose facts about specific community problems in a public forum.
- Present information about steps taken to reduce or address problems.
- Enable community members to learn about healthy lifestyles.
- Increase the visibility of diabetes and its related problems.
- Recognize important accomplishments of groups and individuals.
- Disclose the work done by the coalition and volunteer SUGAR Helpers.
- Encourage others to become volunteer SUGAR Helpers.
- Supply facts for grant writing, fund raising, and media reports.
- Influence social norms of the community.

Annual Reviews

It is important that an annual review or evaluation process occurs. This annual evaluation plan should be something determined as you begin your program. Even if the annual report is brief, this record is essential. If this is not addressed in the planning stages, it may be neglected and opportunities are lost.

Find Success and Keep Up the Good Work!
Annual Review Activities
Describe 3 or 4 Ways Annual Reviews or Evaluations Will be Useful for Your program:

Community Goals
Once you have identified your coalition members, you may need to decide if a smaller advisory board group is needed. Sometimes large coalitions make it difficult to complete work. The election or appointment of a smaller advisory group that meets more often than the larger coalition may be helpful for timely completion of some tasks. However, if your group is smaller, an advisory group may not be needed. These are decisions that your local group will need to make.

Depending upon the level of your group’s formality, you may want to consider whether by-laws need to be established as well. These can help assure that the needed policies and procedures are developed and in place. However, if another group has already been established and the inclusion of the Diabetes: A Family Matter program is to merely be incorporated, there is likely not a need to consider bylaws. However, you may still want to develop policies and procedures to assist the effectiveness of your local program.

It is important that you have input from all involved as you establish and approve your program goals. Group members need to be in agreement about the purposes of the Diabetes: A Family Matter program. Agreement about mission, vision, and program goals provides clarity about the work to be done. Program goals provide a clear way to communicate your work to community members. Annual evaluation of the effectiveness of the strategies used to achieve program goals should occur every year.

Making a Difference
It is essential that you are able to speak to people in your community about the effectiveness of your program. Others will be anxious to become involved and offer continued support if they believe what is happening is valuable. It is important to collect both process and outcome evaluations. Process evaluations are ways to measure how effective what is being done is in meeting the program goals. Processes can be either helpful in achieving goals or become barriers. Careful evaluation of the things you do and the ways you do them can help appraise the efficiency and quality of strategic efforts.

Outcome evaluation measures whether you actually met the goals set or if you did not meet them totally, then what accomplishments can be described in moving towards the program goals. The nice thing about evaluation is that you have really already decided ‘what’ you will evaluate when you set your program goals. The logical next step in goal setting is actually being able to say to the community, “We DID it! We got 100 people educated.” You will be able to do that through a ‘process’ evaluation. In terms of an outcome evaluation, the longer term community
improvements to the lives of those living with diabetes will improve. The longer term goals you set will be able to be evaluated as ‘outcomes’ in your community.

**Examples of Process Evaluations:**

- Evaluate volunteer satisfaction with educational sessions.
- Records of volunteer monthly activities.
- Effectiveness of strategies to attract community people to a health fair.
- Determination of whether money spent to advertise an event resulted in expected attendance numbers.

**Process Evaluations**

List 4 or 5 Processes You Will Want to Evaluate in Your Program:

**Examples of Outcome Evaluations:**

- Numbers of events or activities that volunteers accomplish.
- Numbers of community people attending a specific event.
- Numbers of volunteers attending monthly support sessions.
- Records of reduced BMIs in adolescents over a three year period.

**Outcome Evaluations**

List 3 to 5 Outcomes You Will Want to Evaluate in Your Program:

**Record of Personal SUGAR Helper Goals**

You should consider how you will handle ongoing individual goals. The evaluation process for your coalition should include a review of the personal goals set by volunteer SUGAR Helpers. A report of these goals and the outcomes should be recorded as part of your annual evaluation report and shared with your coalition and/or project team.
At the conclusion of the SUGAR Helper training program, each volunteer should write personal goals. At the end of the first year of volunteer activities, it would be a good idea to review these goals and related outcomes as a group. This goal evaluation should be considered in the effectiveness of your program.

Volunteers that are practicing healthy habits and attaining personal goals are more apt to be effective role models for others in the community. Completion of personal goals will provide some indication of volunteers’ personal satisfaction in addressing program goals.

**Keep Records**

It is important that you decide what types of records will be kept and who will have the responsibility for the various tasks involved in managing these records. Remember to involve SUGAR Helpers in doing this kind of work. They can help plan meetings, organize activities, and manage record keeping.

As a diabetes educator who has decided to develop a diabetes program for your community, you need to keep program records. These records serve as documentation of the program initiatives as well as program successes. Records can also help you retain information about what worked and what was less successful. Asking volunteers to complete evaluation forms at end of your education sessions. Records of the bi-weekly or monthly activities, and an annual satisfaction survey are examples of other things to include in an evaluation of your program.

**Some Things to Monitor:**

- Contact lists of local persons and groups that might be interested in the events or activities sponsored by the *Diabetes: A Family Matter* program.
- Event attendance.
- Sponsor contributions.
- Individual donations.
- Organization of and planning timelines for events.
- Contact information for volunteers.
- Contact information for community partners.
- Levels of volunteer participation.
- Program evaluations.

**Record Keeping**

Describe at least 4 or 5 Record Keeping Areas Needed for Your Program:

**Write Reports**

Set a date for when reports will be completed. Sometimes writing reports seems less important than the involvement that happens around planned events and activities.
However, it is important to not underestimate the importance of doing this annually. These reports give you the clout to speak to others about community needs and accomplishments in meeting goals. The community partners or local champions who are helping by supporting or funding projects will want to know their money is making a difference. Community members and partners want to support things that are effective and make a difference for local residents. Local reports also give you a way to communicate with local and state legislators.

**Keep the Community Informed**

Reports should not merely be placed in a file drawer! Become a “flag-waver” and celebrate your program’s successes. Give credit to those who have worked tirelessly. Talk about the differences being made locally. Discuss the number of positive changes that are occurring in people’s lives. People REALLY do want to hear some good news! Find ways to share stories that describe the positive impact of community members working together on health issues.

Be a “flag-waver”.... Publicly celebrate your successes! Give credit to those who have worked tirelessly. Talk about the differences being made locally. Tell others about the positive changes being made. Let others know how they can get involved.

What you learn from your annual evaluation should be shared broadly with the community. Ask the local newspaper to do a story. Go on local radio programs and talk about what you have accomplished. Give presentations to local groups. Ask the community hospital to do a write-up about the program. Remember, you do not have to be the only one sharing the good news of the work you have accomplished. Get your coalition or project team members involved. Have SUGAR Helpers share highlights from the report where they live and give the news to groups where they belong. Everyone can spread the news about improved health, diabetes prevention, and better diabetes self-management.

**Informing the Community**

List 3 to 5 Ways You Will Share Information about Your program with the Community:
REFERENCES


REFERENCES


## Diabetes: A Family Matter Program Goals

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<thead>
<tr>
<th>Program Goal #1</th>
<th>Strategies to Meet Goal #1:</th>
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Position Title: SUGAR Helper
“Sugar” is a term used by many people in Appalachia when they are talking about diabetes. In this program, SUGAR stands for Support to Unite Generations in the Appalachian Region. Volunteer SUGAR Helpers work together to increase health and prevent diabetes. No prior knowledge or background in diabetes care is needed. A six-week education program is provided to increase volunteer’s knowledge and skills.

Major Objectives:
1. Make diabetes visible in [name of your community].
2. Assist in planning and holding family and/or community events or activities around diabetes prevention, healthy living, and diabetes topics.
3. Assist individuals and families to prevent diabetes and increase healthy living behaviors.
4. Serve as a resource for people with diabetes, as well as their family members, and friends.

Major Responsibilities:
The main roles are to work with others in the community to increase knowledge about health and wellness, increase healthy eating and physical activity of individuals and families, and increase understandings about diabetes prevention and care.

1. Participate in a volunteer SUGAR Helper six-week educational training program.
2. Work with diabetes educators, health professionals, and community volunteers to increase local knowledge about healthy lifestyles and diabetes prevention.
3. Meet with individuals, families, or groups regularly to increase visibility of living well with diabetes.
4. Take part in community events and activities related to health promotion, diabetes prevention, and diabetes management.
5. Turn in bi-weekly reports.
6. Attend support sessions.

Qualifications:
While having knowledge about health and diabetes already is good, it is not required for becoming a volunteer SUGAR Helper. The education and support sessions will provide the facts needed for volunteer roles.

1. Interested in improving personal health.
2. Interested in being involved in activities and events to improve knowledge about health of local individuals and families.
3. Interested in being involved in activities and events to improve health behaviors of local individuals and families.
4. Interest in needs and concerns of individuals and families living with diabetes.
5. Desire to be personally involved in preventing diabetes in the community.
6. Ability to communicate openly with others.
7. Willing to work with persons from different educational, economic, cultural, or racial backgrounds.

Supervision:
Local diabetes educator or health professionals knowledgeable about diabetes will provide ongoing support. Volunteer SUGAR Helpers work with professionals and other volunteers to provide community conversations, events, and activities pertaining to healthy lifestyles and diabetes.

Training:
1. Attend an initial six-week educational training session that is provided by a local diabetes educator and/or other health professionals.
2. Attendance at on-going support sessions where continued education is provided.


**APPENDIX C**

**Time Requirement:**

No set amount of time must be dedicated, but it is suggested that you would provide a minimum of 2 to 4 hours weekly in volunteer activities. Volunteer SUGAR Helpers take active roles in working with others to increase health of community persons and their families and prevent disease.

**Length of Commitment:**

A one year commitment is requested. You may want to participate longer, but this is a decision that you make at the end of each year’s service.
It will be useful to prepare a flyer or a card that you can give to persons that might be interested in becoming a volunteer SUGAR Helper. Whenever you speak with someone that might be interested, be sure to they know ways to contact you in the future. Keep a record of those who seem interested and check back with them to answer other questions. Some people may be timid and need extra encouragement to take the first steps in becoming a volunteer.

Go to the online Diabetes: A Family Matter website and you will find additional things to help you in developing a media campaign for your program and volunteer SUGAR Helper recruitment materials.

<table>
<thead>
<tr>
<th>Diabetes: A Family Matter</th>
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<tbody>
<tr>
<td><strong>Name of Diabetes Educator:</strong></td>
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<td><strong>Phone:</strong></td>
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<td><strong>E-mail:</strong></td>
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<tr>
<td><strong>Location for Educational Training Sessions:</strong></td>
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<td><strong>Dates for Sessions:</strong></td>
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This is an example of the kinds of information you might want to collect from those that volunteer to become local SUGAR Helpers. You may have another form that you already use that you might want to adapt. Be sure to carefully consider the kinds of information you will need to know about your volunteers. This information can assist you in making decisions about the kind of activities to encourage individual volunteers to do alone. The information can also help you identify talents and experiences of smaller numbers of volunteers that might be interested in working on individual projects. Volunteer information can assisted you in telling others in the community about those already participating and can help you assess other skills or talents needed and also places in the community where you have not yet reached. Finally, summaries of some of this information will be useful in your annual evaluation reports.
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<th><strong>Volunteer Application</strong></th>
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<td><strong>Current Employer:</strong></td>
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<td><strong>List previous volunteer experiences:</strong></td>
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<td><strong>Places or things you currently do as a volunteer:</strong></td>
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<td><strong>List the groups where you belong or now take part or have in the past (church, 4H, scouts, PTA, civic or community groups, professional organizations, and others):</strong></td>
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<td><strong>Leadership roles you have had in either work or volunteer activities:</strong></td>
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APPENDIX F  Sample Outline for Volunteer SUGAR Helpers Educational Sessions

It is likely that you already have a diabetes education program that is regularly used. For example, you may have a program to teach persons newly diagnosed with diabetes. You may want to include parts of that program in your educational sessions. Volunteer SUGAR Helpers need to know about healthy lifestyles and diabetes prevention and care. Volunteers also need to learn ways to communicate effectively with individuals, families, and community groups. They need to know about family support and care, empowerment, cultural sensitivity, and low health literacy. Some volunteers might need to gain better understandings about the community and learn about record keeping tasks. Include these ideas in your training sessions.

Think about ways you can adapt educational materials you currently use to include in your educational training sessions. Many excellent resources are available online. See the online Diabetes: A Family Matter website www.diabetesfamily.net to find links to organizations and groups where resources can be found. Also, review the program’s toolkit materials and activities to see what things you might want to include.

It might be helpful to use at least one of the toolkit materials and/or activities at each of your volunteer sessions. You might also want to plan how you will use these in future volunteer monthly Support Sessions. These tools will be useful to volunteers as they work in their families, towns, and local groups. You can encourage volunteers to begin using some of these activities during the time of the training sessions. Choose an activity for volunteers to use each week. At each training session meetings allow time for volunteers to share outcomes of using the activity during the week. Use brainstorming whenever new ideas are introduced to volunteers and encourage them to identify various ways the activities could be used. Then, at the follow-up sessions, use problem solving to identify things that can be done next time to make the activities more effective.

This outline provides suggestions for things to consider. The program you develop should be what best fits your local community and meets your volunteer’s needs. Please take time to share what you do and ideas to include on the Communication section of the program website.

Session I:
Overview of Diabetes: A Family Matter Program
• Ice-breaker
• Diabetes: Just the Facts (basic information about diabetes)
• Overview of Healthy Lifestyles (set a single personal healthy goal to extend over the 6 educational sessions)
• Overview of the SUGAR Helper Manual
• Roles of Volunteers
• Assignment to read part of manual in preparation for next session
• Toolkit Activity for volunteers to work during the time until the next session (Use brainstorming to identify ways and places to do the activity)

Session II: Health and Wellness
• Ice-breaker
• Healthy Lifestyles: Discuss personal goals
• Communication with individuals, families, and groups
• Overview of the Diabetes: A Family Matter website
• Assignment to read part of manual in preparation for next session
• Review outcomes from previous weeks Toolkit Activity (Do problem solving to consider ways to increase the effectiveness of the activities next time used)
• Toolkit Activity for volunteers to work during the time until the next session (Use brainstorming to identify ways and places to do the activity)
Session III: Prevention [consider using the CDC Power to Prevent program]

- Ice-breaker
- Prevention of Diabetes
- Healthy Lifestyles: Discuss personal goals
- Physical activity
- Family care
- Literacy, health literacy, and low health literacy
- Review Series of Family-Focused Brochures: Brainstorm ways to use them.
- Assignment to read part of manual in preparation for next session
- Review outcomes from previous weeks
- Toolkit Activity (Do problem solving to consider ways to increase the effectiveness of the activities next time used)
- Toolkit Activity for volunteers to work during the time until the next session (Use brainstorming to identify ways and places to do the activity)

Session IV: Diabetes Self-Management [consider AADE Healthy 7 or aspects of your local diabetes education program]

- Ice-breaker
- Diabetes Care Management
- Healthy Lifestyles: Discuss personal goals
- Interdisciplinary teams and medical management of diabetes
- Film: Living with Diabetes in Appalachia
- Assignment to read part of manual in preparation for next session
- Review outcomes from previous weeks
- Toolkit Activity (Do problem solving to consider ways to increase the effectiveness of the activities next time used)
- Toolkit Activity for volunteers to work during the time until the next session (Use brainstorming to identify ways and places to do the activity)

Session V: Prevention [consider using the CDC Power to Prevent program]

- Ice-breaker
- Prevention of Diabetes (continued)
- Healthy Lifestyles: Discuss personal goals
- Cultural sensitivity
- Healthy eating
- Assignment to read part of manual in preparation for next session
- Review outcomes from previous weeks
- Toolkit Activity (Do problem solving to consider ways to increase the effectiveness of the activities next time used)
- Toolkit Activity for volunteers to work during the time until the next session (Use brainstorming to identify ways and places to do the activity)

Session VI: Diabetes Self-Management [consider AADE Healthy 7 or aspects of your local diabetes education program]

- Ice-breaker
- Diabetes Care Management from Family and Community Perspectives
- Show and Discuss SUGAR Plays
- Review outcomes from previous weeks Toolkit Activity (Do problem solving to consider ways to increase the effectiveness of the activities next time used)
- Discuss Support Sessions, Next meeting Time, Specific Activities Planned (individual, family, groups, and larger community)
- Write Personal Long Term 1 Year Goals
A total of 3 or 4 goals should be set for the year. Think about things you would like to change. Be sure these are things that are important to you. Choose a goal you believe that you can reach. On the basis of 1 to 10 with “10” being the highest level of confidence. Be sure that you have a confidence level of at least “7” for each goal you set. Choose at least one goal that has to do with your personal health. The others should pertain to what you would like to accomplish as a volunteer SUGAR Helper.

**Personal Health Goal:**

✔ My Goal:  
Confidence:

**Volunteer SUGAR Helper Goal #1:**

✔ My Goal:  
Confidence:

**Volunteer SUGAR Helper Goal #2:**

✔ My Goal:  
Confidence:

**Volunteer SUGAR Helper Goal #3:**

✔ My Goal:  
Confidence: