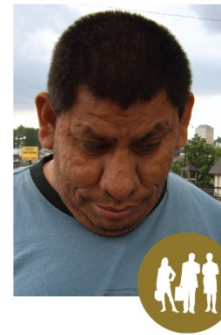




# SHARING OUR STRENGTHS PEER SUPPORT

A PROGRAM OF MISSOURI FAMILY TO FAMILY RESOURCE CENTER | UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD



## Sharing our Strengths Peer Mentor Handbook

Peer mentoring is a crucial component of emotional support for parents, caregivers and individuals experiencing disability. Peer mentors are everyday people who have the ability to listen, support and share common stories.

Mentoring is offered throughout the life course, from the first signs, symptoms or diagnosis through transitions between schools and into adulthood. Decrease stress and isolation

Goals of Sharing our Strengths:

- Increase knowledge and use of resources
- Increase confidence and skills by providing emotional support, information and training
- Enhance the education, understanding and sensitivity of those working with individuals and families
- Encourage people to take on leadership roles locally, statewide and nationally

SHARING OUR STRENGTHS  
MISSOURI FAMILY TO FAMILY RESOURCE CENTER

*Missouri Family to Family Resource Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.*

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## Acknowledgments

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**A special thank you to the late Betsi Santelli for the information and support provided at the preliminary meeting and throughout the development of SOS.**

- **The Beach Center on Families and Disability – University of Kansas**
- **Family to Family Network of North Dakota**
- **Parent to Parent of Pennsylvania**

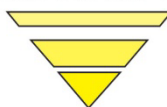
**The original guide was compiled in 2002 and has been updated over this last year (2012) by faculty of the Institute for Human Development (IHD), a University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD).**



**Institute for Human Development**

A University Center for Excellence in Developmental Disabilities (UCEDD)

**DEVELOPMENTAL  
DISABILITIES**



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Welcome to the Missouri Family-to-Family Disability & Health Resource Center (MoF2F). This guide is designed to help you participate in volunteer opportunities and gain a better understanding of peer mentoring.

### What is Missouri's Family-to-Family Health & Disability Resource Center (MoF2F)?

MoF2F provides information, connects individuals with disabilities and/or special health care needs and families to peer support, and provides leadership and training opportunities so they are well informed, hopeful, connected within their communities and aware that they are not alone in their experience. MoF2F also assists agencies and service providers through informational support and training to better meet the diverse needs of families and individuals with disabilities and special health care needs.

MoF2F is a collaboration between:

- UMKC-Institute for Human Development (UCEDD)
- DMH Division of Developmental Disabilities
- Missouri Council for Developmental Disabilities
- Missouri DHSS Bureau of Special Health Care Needs

When contacting MoF2F, you are connecting to people with first-hand knowledge of disability related issues who have experience as parents, family members, and/or individuals with a disability and/or special health care need.

MoF2F also houses Sharing Our Strengths (SOS), Missouri's chapter of Parent-to-Parent USA. SOS is a statewide network of people connected to disabilities and/or special health care needs including parents, siblings, extended family members, self-advocates and professionals who are interested in connecting with others based on their needs, interests, and challenges. SOS is not an advocacy organization and is not able to represent individuals or families in meetings, speak for individuals and families, or represent

groups of individuals or families. SOS offers an opportunity for individuals to become a mentor to others and be matched to people who are looking for information and support.

### Core Beliefs

MoF2F believes all people, including those with developmental disabilities and/or special health care needs:

- deserve love and nurturing unique to their own families.
- have the right to live independently in their communities, work productively for fair compensation, and participate fully in community activities.
- deserve full inclusion in their communities – and their communities deserve their inclusion.

***“Having the ability to visit with a parent who is walking in my shoes is awesome. I am very thankful for the mentorship program.”***

### People First Language

People first language respects everyone's differences and diversity. Disability is not “the problem.” We need to rid our vocabulary of the word “problem” when talking about people's needs. People First Language puts the person before the disability, describing what he or she has, not what he or she is. A person with glasses does not say, “I have a problem seeing.” Instead he/she says, “I wear (or need) glasses.” Recognize that what we call a problem is actually a need.

It is essential that mentors use people first language. If people with disabilities are to be included in all aspects of our communities; in the ordinary, wonderful, and typical activities most people take for granted; they must talk about themselves in the ordinary, wonderful, typical language others use about themselves. They are parents, children, siblings, friends, employees, celebrities, and scientists, just to name a few. Most importantly they are people first.



In order to be inclusive, think about the power of the words you use. Do we include people or isolate individuals and groups? Many words in our society act as labels that lead to negative stereotypes and undervalue the people they are describing.

**Guidelines for Using People First Language:**

- Do not refer to a person’s disability unless it is relevant to the conversation.
- If making comparisons between people with disabilities and people without disabilities, say, “people without disabilities” rather than “normal” or “able-bodied.”
- Emphasize abilities, not limitations!

Language is powerful. Words build people up or tear them down.

**Examples of People First Language**

Say...	Instead of...
Individual with a disability	Handicapped/disabled/invalid
Individuals without disabilities	Normal people
Person with intellectual/developmental disabilities.	Mentally retarded/retarded
People with a mental illness A person with a psychiatric illness/disability	Mentally ill Crazy/ psycho
A person who has a learning disability	Learning disabled
He/she has a hearing impairment/loss	The deaf
A person who is deaf and cannot speak A person who uses a communication device/synthetic speech	Is deaf and dumb/mute
A person who is blind/has a visual impairment	The blind
A person who has epilepsy People with a seizure disorder	An epileptic A victim of epilepsy
A person who uses a wheelchair/has a mobility impairment A person who walks with crutches	A person who is wheelchair bound/confined to a wheelchair A cripple
A person who has quadriplegia/with paraplegia	A quadriplegic/paraplegic
He/she is short of stature	A dwarf/midget
He/she has a congenital disability	Has a birth defect
Accessible busses, bathroom, parking, etc.	Handicapped busses, bathroom, parking, etc.
A person who has....	Victim of...

Information Courtesy of People First of Missouri. <http://www.missouripeoplefirst.org> and SABE. *People First Language: The Basics*. Retrieved from [http://www.sabeusa.org/user\\_storage/File/sabeusa/People%2520First%2520Language%2520Manual.pdf](http://www.sabeusa.org/user_storage/File/sabeusa/People%2520First%2520Language%2520Manual.pdf)

### Key Terms

**Mentor:** a self-advocate, parent, family member or professional who volunteers to be matched to a requestor based on needs, shared interests, and challenges. Mentors share experiences, practical information and resources and offer emotional support. Mentors receive training to provide support in positive ways.

**Requestor:** a person seeking information and/or support. A requestor might be a new parent, a parent whose child has recently been diagnosed or someone who is going through a challenging time. They might also be involved with a person transitioning from living in an institution to living in the community. A requestor can be a self-advocate or a family member of a person with a disability or special health care need. A requestor may also be a professional who wants to gain more knowledge related to the field of disabilities or special health care needs.

**Family Member:** parents, siblings, step-parents, foster families, grandparents, aunts and uncles or anyone who has a close relationship with a person with a disability. Family members can be matched with other family members, self-advocates, or professionals.

**Self-Advocate:** an adult with a disability seeking social supports, information or other types of support from other self-advocates, family members or professionals.

**Professional:** someone who works with people with disabilities and/or families. Examples include direct support staff, case managers, therapists, teachers, paraprofessionals, medical staff, etc. Professionals can request to be matched to others in their field or to parents, self-advocates, or other professionals.

***“Mentoring helps me know that I am not alone.”***

### What is a mentor?

A mentor is someone who provides support through listening and offering information. Mentors deliver an important service by modeling a positive attitude toward their own child, loved one, or self and by demonstrating through example that it is possible to live a happy and productive life.



JUDY'S BRAND OF  
"IN-YOUR-FACE"  
SELF-ADVOCACY FIRST SHOWED  
ITSELF AT AN EARLY AGE.

### Who can mentor?

Any volunteer with Missouri's Family-to-Family Health and Disability Resource Center who has received mentor training can be a Sharing our Strengths peer mentor. These individuals are warm, friendly, and engaging. They are non-judgmental and able to listen, allowing the requestor to be the focus of the conversation.

Participation in Sharing Our Strengths (SOS) is open to families of individuals with disabilities or special health care needs including parents, siblings, grandparents, and extended family members. Self-advocates are encouraged to participate in SOS. Professionals who interact with children and adults with disabilities and special health care needs are also welcome.

### Characteristics of a Mentor:

Do you?

- View all people as valuable regardless of their abilities
- Accept that each person has strengths and weaknesses
- Participate in and monitor the services provided for yourself or your family member
- Advocate for change
- Have a positive relationship/attitude about the professionals you encounter
- Feel at peace with the choices/decisions you have made
- Work through any anger or fear surrounding disabilities and/or special health care needs
- Believe anyone can learn and improve
- Accept your own strengths and weaknesses
- Have time to be involved in Sharing Our Strengths and support others

Are you?

- Willing to share your experience
- Concerned about others
- Non-judgmental
- A good listener

Can you?

- Identify the needs and feelings of others
- Provide support without making decisions for others
- Convey a sense of calm assurance
- Handle confidential information without discussing it with others
- Become personally involved and cope with the problems of others without being hurt or overwhelmed
- Accept rejection without taking it personally
- Work without a lot of praise or recognition
- Give to others without expectations of something in return
- Share personal experiences
- Express yourself well

### Why are mentors needed?

Self-advocates, parents and family members may sometimes feel alone or helpless. People who work with or are preparing to work with those

who have disabilities or special health care needs may feel overwhelmed. Talking with someone who has experienced a similar situation can help them feel less alone, more hopeful, and better prepared.

It is beneficial to have guidance about care and day-to-day coping with the effects and life changes of living with a disability or special health care need. Sharing ideas can bring a sense of security to parents wondering what to do when their child does not fit the usual pattern of growth and development. The parent can also develop concrete skills, questions and hope for the future.

Transitions throughout the lifetime can be a source of stress and anxiety.

For example, transitions from:

- receiving services from First Steps to Early Childhood through the school district,
- elementary to middle and high school
- school to adult life
- living in an institution to living in the community

Talking to someone who has experienced a similar transition can be a source of comfort and valuable information.

Self-advocates can share information and ideas to help build confidence in making life decisions. They can develop and improve their advocacy skills, as well as forming friendships and other relationships.

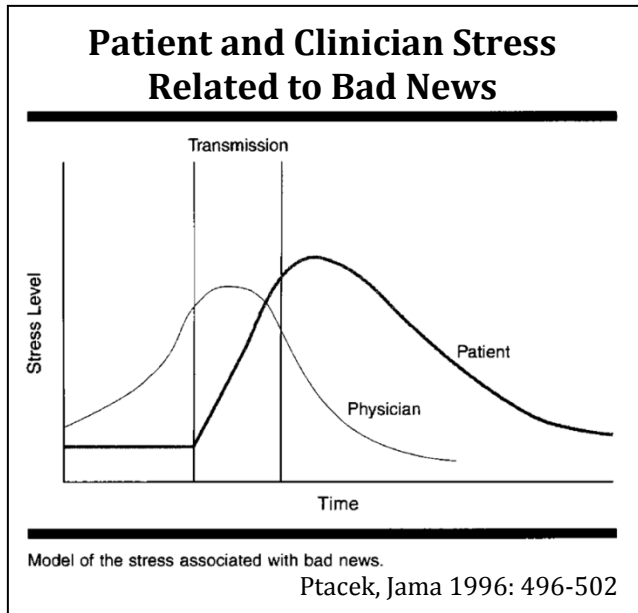
Self-advocates and children with disabilities may use a variety of services. Locating and negotiating through a maze of needed programs and interacting with a range of professionals are skills that mentors can teach. The person who has successfully learned to advocate for their child or for themselves has a unique and valuable set of skills to share with others.

Professionals can benefit by sharing practical information and specific suggestions with others in their field. They may also benefit from talking directly with self-advocates or families to better understand the issues they face.

### How Important is Peer Mentoring?

Two studies addressing how doctors give bad news to patients give us some insight into what parents and individuals experience when receiving critical information while experiencing heightened levels of stress.

Think back on your own experience when you first heard a diagnosis. What was your initial reaction? How thoroughly did you understand the information?



In the figure above the clinician’s stress level peaks while relating information to the patient. The patient’s stress level continues to rise beyond the actual information session with the clinician.

Another study focused on parents receiving bad news about their child. After the initial “bad news” session a separate information session was given to each set of parents. You can see in the following summary that over half the parents did not comprehend much of the information from the second session.

### People receiving bad news may not remember much

Three months after parents received bad news:

- 12 of 23 sets took in “little or none of the information given”
- 4 of 23 sets denied that a separate information session had occurred following the bad news session
- 10 of 19 sets remembered the information session, but didn’t understand the content

Eden, Pall Med1994: 105-114

Peer mentoring is crucial in reaching out to those who have experienced great stress but who may not remember much of the critical information they initially received. Mentors can guide requestors through emotional times and help them understand what lies ahead.

### Sharing Personal Experiences

Person to person support means that people use their own experiences as a guide to help others in similar situations. Mentors have found the following guidelines useful in helping to know when to share their own experiences with requestors.

### Sharing personal experiences can be useful to...

- introduce yourself or your family to a requestor
- let the requestor know they are not alone
- help the requestor to discuss a problem that is difficult to talk about
- show acceptance of the requestor’s decisions or actions
- introduce a new topic
- illustrate a point

It is important to stress to the requestor that each situation is unique. When you use your own experience you might say:

“This worked for me, but I can’t say it will work for you. I just wanted to share it with you because it might be an option you have not thought of yet.”



Mentors provide practical information about community and local supports, systems, or resources. They also provide emotional support by sharing a common experience so that requestors know that they are not alone and understand that their feelings are natural. It often helps a requestor to have someone to talk to at different times throughout the life course. Mentors may also provide referral resources. If you don't know the information or resources a requestor needs call the SOS Coordinator or Information Specialist for help.

### Role of a Mentor

As a mentor you have the opportunity to provide a listening ear or a shoulder to cry on, allowing the requestor to express honest emotions. It is important that you listen with acceptance, remaining open-minded and non-judgmental.

Mentors offer encouragement, emotional support, and information. You guide the requestor in learning how to make informed, responsible choices by providing direction and guidance as needed while allowing the requestor to make his/her own decisions. You are also sensitive to the requestor's feelings and privacy.

Mentors keep the conversation focused on the requestor's feelings and perception of the situation while emphasizing their rights and responsibilities. Urge the requestor to discuss any concerns about quality of care or services with the professional(s) providing the care. Respect the confidentiality of the relationship.

Look for opportunities to help the requestor get involved in typical activities within their community. Inform the requestor about local support groups, conferences, and other resources. Encourage the requestor to take on leadership roles locally, statewide, or nationally when they are ready.

### Rights of a Mentor

Mentors are the most valuable resources of SOS and have the right to be:

- Assigned to tasks which are suitable to your expertise, skills, and preferences
- Trained properly for the assumption of responsibilities and provided with continuous support and training opportunities aimed at improving skills
- Involved in making suggestions and assisting in planning for the organization
- Treated with respect and given sound guidance and support from staff
- Recognized with expressions of appreciation
- Assured that your personal information will remain private
- Able to say "no" if you cannot accept a match.

### Responsibilities of a Mentor

Mentors are responsible for initiating contact with requestors and documenting contact information.

It is important to respect confidentiality and not refer to other families by name or discuss the identity of another SOS mentor or requestor with anyone other than SOS staff. It is also important that you don't discuss details that a requestor has not yet mentioned (you may know information from the intake data provided by SOS staff).

Set limits on your time and availability. It is not your job to provide personal services (babysitting, transportation, etc.) or tangible support (money, food, clothing, etc.). Remember that you are not alone as a mentor. Contact SOS support staff for help as needed.

You are not a medical professional and it is not your job to give medical advice. It is important that you do not give opinions on specific doctors, nurses, hospitals, or other professionals, since different people interpret the same professionals differently and routines vary among agencies and institutions.

**Why don't mentors give advice?**

Since requestors have problems and concerns that may make them feel insecure, we can unintentionally set ourselves up as "authorities". Sometimes giving advice causes more harm than good. You may have a lot of information to offer, but keep in mind the dangers associated with giving advice:

- The requestor is more familiar with their family culture and support system. They are more likely to experience success if they can work out their own solutions and may already know subconsciously what needs to be done.
- You may not know the real problem. Be sure all of the necessary information has been communicated.

- The requestor may just need to express their feelings and hear their own ideas out loud.
- Receiving advice may make the requestor feel patronized.
- Giving advice draws you directly into the problem-solving process, which can prevent the requestor from taking responsibility for developing his/her own solutions.
- Receiving advice may foster dependency, instead of self-reliance and empowerment.

A mentor does not discuss topics that might make the requestor feel uncomfortable. Our values, cultures, and families are all different. There may be times when you find that a requestor asks more of you than you can or should do.

If a requestor...	Try...
Is unsure of whether or not to try medication	Offering information on the subject. Talk from experience, if you have it. If you don't know, be honest.
Says they don't know how they are going to get through a situation	Providing emotional support. Ask them what they mean and give them time to express their feelings.
Is concerned about side effects or services provided	Referring the requestor back to the service provider. There may be circumstances that you don't know. Responding solely on experience can be confusing and undermine the requestor's relationship with the service provider.
Is unhappy about their child's educational program or other service	Helping him/her to clarify the problem. Your goal is to help define the problem and provide access to the information and resources. This way they can develop the skills to be able to solve their own problems.
Asks about the best program for his/her child	Asking questions to help the requestor think about what is best for their child and narrow down the possible choice. Offer strategies and resources, which might help them make their own decision.

**“Having a mentor who can talk to you from a perspective of someone who knows what it is like really helps me understand what my child is going through.”**

### Matches (type and length)

- 1) **Quick match:** a match consisting of one phone call that focuses on a particular issue or question
- 2) **Traditional match:** a match consisting of a minimum of four contacts by phone or email over an eight week period
- 3) **Extended match:** an ongoing match over a one year period, with minimum contact of once per month (not typical)

### Match Criteria

- Requestors are matched to a mentor as close as possible to their specifications
- Considerations include: diagnosis; age of child or individual; family structure; racial, religious or cultural factors; geographic location or any specific concerns of the requestor
- If no match is available on the precise criteria requested, a broader category may be used
- If necessary to meet the needs of the requestor, matches with more than one mentor might occur

### Before the match

- Mentor is contacted by SOS coordinator
- Coordinator presents specifics and length of match
- Mentor decides whether to accept match
- Once accepted, SOS coordinator gives mentor contact information for the requestor

### Initial Contact with the Requestor

- Make contact with the requestor by phone or email within 24 to 48 hours.
- Record information regarding date, time, length and purpose/results of each contact on the Mentor Contact Log provided by SOS.
- Notify coordinator that contact has been made.
- If contact cannot be made within 3 days, notify SOS coordinator for follow-up.

### Ongoing Contact

- In general, follow-up within one week (in crisis situations, or when an individual is very upset, it may be necessary to call more often)
- The amount and kind of continued contact depends on the needs and desires of the requestor and the availability of the mentor.
- It is best to not rely solely on the requestor to contact you. Taking the initiative and reaching out to the requestor often provides the needed support when they may be feeling too stressed or overwhelmed to ask for help.
- Occasionally, you may feel the need to set limits on your availability to the requestor or may feel troubled about your interaction with them. In these cases, contact SOS staff for assistance.
- Update the Phone Log on an ongoing basis. The coordinator may ask you about the type and frequency of contacts at the conclusion of the match period.
- At the conclusion of a match, the requestor will be asked to complete a satisfaction survey.

### Problem Solving

This can best be thought of as assisting an individual to prioritize, or create a “to do” list. Writing down pressing issues and concerns will lessen the load, create a flow of thought, and promote success as the requestor is able to check off completed tasks.

### Steps

- **Identify Needs:** What is one immediate need that can be resolved successfully? What must happen to take care of the problem?
- **Discuss Options:** What actions fit the requestor’s family situation? Is more help needed with problem solving or does the requestor just need a supportive listener?
- **Make a Decision** The requestor chooses a course of action. Your role is to make sure that he/she understands any laws, practices, responsibilities, etc. that may limit choices. Be sensitive to the diversity of family

values/customs, shaping choices. What should be done first? What can wait vs. what is time sensitive?

- **Take Action** The requestor takes action. Help him/her be successful: call, e-mail, follow-up!

- **Evaluate the Results** Help the requestor review the experience to become more effective in the future. What happened with each call/contact? How did things turn out?

### Dealing with Emotions, Feelings, and Reactions

Stages	Common Feelings	Common Behavior	How to Handle Each Stage
Shock	Numb Detached/Removed Hysteria	Withdrawn Silent with little response Hysterical, out of control	Accept each person's reactions as normal. Avoid trying to make others act your way.
Panic	Very anxious, helpless Wish to run away Overwhelmed, tense	Cannot plan things, disorganized Forgets things	Let feelings happen, don't hold it all in. Allow others to take over some daily activities for you. Let reality hit you.
Denial & Disbelief	Overwhelmed, helpless Full of doubt, anxious Physically rundown	Search for another doctor's opinion. Resist change of plans. Refuse to talk about it. Deny that you could have a child "like that". Sleep a lot without feeling rested. Talk about aches and pains. Keep busy and do not allow time to dwell on it.	Allow yourself to delay acceptance of the situation until ready to accept. Allow yourself to delay talking about it until you are ready. Get extra rest, eat nutritious foods. Turn over chores to family and friends. Do not apologize for getting another opinion. Remember it's alright to talk about your own aches and pains. Begin to find out facts.
Anger & Fear	Angry at everyone Frustrated Fear power of own anger Bitter	Abrupt, cold, interrupt people Blame others, say "Why me?" Keeps distance from child Lash out at doctors, nurses, family, others	Don't put yourself down for feeling angry. Try to limit angry attacks, say, "I'm just angry at the whole situation." Apologize if you intentionally hurt someone. Realize that others may not know what to say or how to help you. Don't be surprised that you keep getting angry.
Sadness & Despair	Guilt Shame Emptiness Sadness	Blames self. Puts self-down Depressed-slow to react. Crying, loss of appetite, inability to sleep irritable. May have strong or no sexual desires. Keeps distance from friends with children.	Say often, "No one is to blame, not even me." Expect to feel depressed and tired. Seek someone to talk to about feelings. Seek help in making daily plans. Rest and eat nutritious food. Spend more time with your child.
Hope	Wish for help. Feelings less intense. Waves of depression continue. Fear of future and how to handle it.	Search for reason or cause. Struggle to look for typical aspects of child. See parts of self in child. Says, "Those sad feelings keep coming back."	Spend more time with child. Be realistic and don't cling to false hopes. Get more facts from nurses, doctors, and other parents with similar experience. Accept help from everyone who offers. Expect waves of depression, but less frequent and less intense.
Adaptation	Begins to feel more satisfaction with life. Feel closer to your child/self.	Searches for acceptance from others for self and child. Seeks help from others to correct child's situation or adapt to it.	Actively participate in treatment. Focus on strengths.

## Tips for the First Contact

### When to Call

- When you receive a referral, contact the requestor within 24 to 48 hours.
- If the person is difficult to reach, try calling at different times of the day.
- If you have difficulty making the initial contact, contact the SOS coordinator. Keep trying to contact them in the meantime.
- Be prepared for a long conversation. It is a great relief for a requestor to talk to someone who understands their feelings and concerns.
- Notify coordinator by email or by phone that the requestor has been contacted. Send email or phone coordinator for the next three contacts. If you have been unable to establish initial contact within three days notify the SOS coordinator.

### What to Say

- Introduce yourself. "Hello, my name is \_\_\_\_\_. I am a mentor with Sharing Our Strengths. Is this a good time for you to talk?" (If not, ask when you can call back.)
- Ask the requestor about him/herself, the child, siblings, or the adjustment experiences. Be ready to offer support.
- Focus on how the person is feeling and coping rather than on problem solving. Offer reassurance that all feelings are normal.
- Briefly share your experiences as appropriate. Do not monopolize the conversation with stories of your own experiences. The main point to be made is that you have been there too.
- Ask questions, but don't pry. Ask open-ended questions like "how are you today?" rather than closed yes-no questions like "are you feeling okay today?"
- When speaking to a parent about their child, use the child's name.
- LISTEN with open ears and an open heart.
- Be aware that some people may feel uncomfortable speaking with you at first. Explain that you are there to offer support, not be a social worker. It may be helpful to mention

how support from others has benefited you and your family.

- End the conversation on a positive note. Before you hang up, establish an approximate day and time when you will call again. If **you** wish, you can give the requestor your telephone number in case he/she would like to call you, or you can arrange a time and place to meet.

## Providing Support in an Emergency

***Mentor families have developed the following suggestions for responding to emergency situations:***

1. Keep the Sharing Our Strengths mission in mind. Sharing Our Strengths Network mentors provide:
  - Support
  - Information
2. Listen. Try to understand what the requestor is telling you.
  - Don't express an opinion; realize that you are hearing about the situation from the requestor's perspective.
  - Help the requestor identify immediate needs.
3. Give the requestor local emergency phone numbers. Be very specific about what service is connected with each number.
4. Allow the requestor to talk, if that's what they want. Usually, a few minutes of being listened to helps them feel calmer.
5. Give the requestor the option of calling back, if none of the resources you have given are helpful.
6. Realize that you might not have all of the answers. When appropriate, contact the Sharing Ours Strengths Network office for guidance.

### Ending a Support Relationship

- There is no set time limit for a support relationship. SOS staff will track the match for the specified time listed above, continued contact beyond that is up to the mentor and the requestor.
- Generally, contact with a requestor becomes less frequent as they come to feel more confident and resourceful about making decisions and meeting their own needs or the needs of their child or loved one.
- A support relationship ends when the mentor and the requestor agree it is no longer needed.
- Sometimes a support relationship turns into a friendship, and the two people may choose to continue indefinitely on this more informal basis.

### Reminders

- Say “NO” if you cannot accept a referral when you are contacted by SOS Staff. Telling staff

that it is not a good time for you to accept a match will permit the selection of a mentor who is able to contact the requestor

- If for any reason you feel you cannot provide the support the requestor needs, contact staff to ask them to assign a different mentor. It is better to change mentors than to fail to give the support needed due to a conflict of personalities or other circumstances. Also note that the requestor can always request a different mentor.
- Don't worry about a delay in being matched. Mentors are matched with requestors who have similar needs. This occasionally results in some mentors receiving several referrals while others have yet to be assigned one. Be patient, your time will come.
- Call staff anytime you have questions or concerns (1-800-444-0821)



“It is nice to know I can connect with a parent who won't just speak to me in medical terms.

Having a parent to connect to gives me the answers based on experience.”

### Requirements for Becoming a Mentor

A mentor for SOS must be willing to attend training sessions and activities. The commitment to being a trained mentor is an important component of the SOS mission.

### Obligation of Mentors

Volunteering is a commitment. Mentors agree to do certain tasks and the completion of said tasks without salary does not change the fact that other people depend on the mentor's performance. Before committing the time, mentors should honor all obligations as conscientiously as if they were receiving wages for them.

### Limitation of Mentor Duties and Authority

Sharing Our Strengths mentors will follow all guidelines established in this document and all other materials provided. Any questions regarding policies and procedures should be directed to staff members. Sharing Our Strengths staff are responsible for developing all policies and procedures.

### Code of Ethics

Mentors must be sensitive to the issues of families and self-advocates; appreciate cultural sensitivity; and be non-judgmental. Mentors follow the Network's mission and will not use requestors as a source for self-promotion. Attempting to sell anything to requestors or to engage them in business is strictly prohibited. Advancing your own religious, political or any other personal beliefs that could be intrusive to the requestor is inappropriate and is prohibited.

### Completion of Tasks

Mentors perform duties described in this manual and all other materials provided, and those tasks agreed upon by the mentor and the Network staff. Additionally, mentors will complete any paperwork as specified in this manual or as

requested by staff. Documents submitted are used in the SOS Network's record-keeping and accountability activities and are subject to all policies of confidentiality.

### Financial Assistance/Transportation

SOS staff, mentors, and other volunteers are prohibited from loaning or giving money to others involved in a support relationship, including the requestor or family members. Individuals or families may be offered options and referrals to obtain financial assistance from other sources.

Staff and volunteers will not transport or loan transportation to families or others they may be involved with in their role with SOS.

### Appropriate Matching/Termination of Support

It is an SOS policy that if a match is not beneficial to the requestor or if the match is not comfortable or appropriate for the mentor, the match will cease and another match will be made, if possible.

Support to a referred person or family may be terminated when the issues the person or family is facing seem to go beyond the scope of the SOS support. The decision to terminate support will be made by SOS staff, upon consultation with the families involved, and every effort will be made to see that the individual is referred to the appropriate level of service or care.

### Support and Development

Sharing Our Strengths staff will provide on-going support and training to all mentors and assist with assigned tasks. Opportunities will be provided for mentors to grow and develop in their capacity as supportive family members and self-advocates.

### Gifts

The giving or receiving of gifts by those involved in support relationships, including staff, mentors, and referred individuals and families, is discouraged.

### Domestic Disputes

Sharing Our Strengths staff and mentors are prohibited from being involved in any domestic dispute. Should a dispute occur when staff or a mentor is present, they should leave the situation immediately. If staff or the mentor fears for the safety of the child or other family members, they should call the appropriate authorities, then notify SOS staff of actions taken. An incident report form may need to be completed for our records.

### Use of Drugs and Alcohol

Sharing Our Strengths recognizes that drugs and alcohol can affect the quality of the work environment and family life and seriously jeopardize the health of the user. Therefore, the use of drugs or alcohol, by volunteers or staff, while representing SOS is not allowed.

### Confidentiality

Confidentiality is an important building block of trust. All SOS mentors are required to sign the Confidentiality Statement and strictly adhere to it. Employees and volunteers (mentors) of this program may not disclose information about participating families or individuals, other volunteers or employees, to anyone outside the program without the family or individual's prior consent.

Additionally, information shall not be disclosed within the organization, except on a need-to-know basis. This includes any identifying information concerning current, past or

prospective mentors and referred persons or families, other volunteers, and staff.

As a trained mentor, please do not discuss SOS participants with others. You can discuss general situations, but please, do not mention names or discuss specific details that could easily identify a particular individual or family. The exception to this is when you are discussing a specific family or individual with SOS coordinators.

Please do not discuss doctors, hospitals or other health care providers, teachers, paraprofessionals, schools or school administrators by name. Avoid comments that might be interpreted as criticism of professionals or agencies involved with the individual or family. It is important to avoid causing the requestor any additional anxiety by "comparing notes" in a way that might suggest that they or their child are getting less than optimum care.

Hold in confidence everything the requestor shares with you. If they confide information that you believe someone needs to know, encourage them to consult with the appropriate person or authority. Your actions in this situation depend on the attitude of the requestor and your sense of how crucial it is that the information be shared.

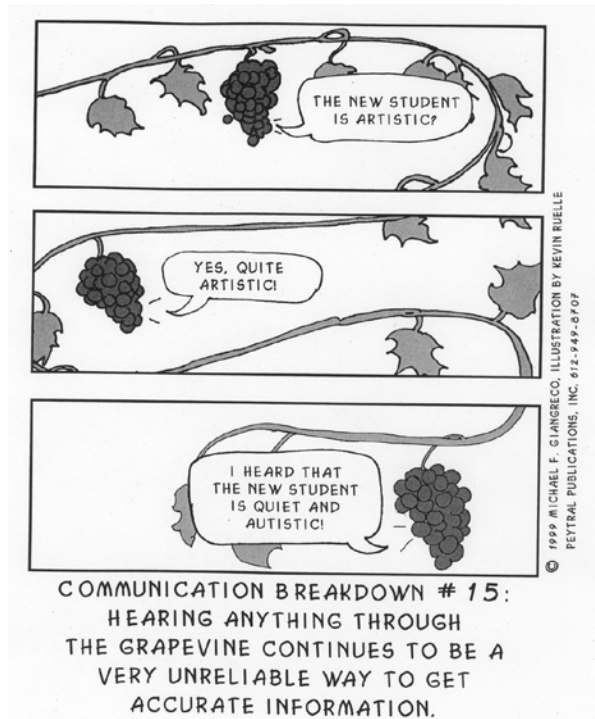
Occasionally, an individual or family will not discuss an important subject with professionals and yet be willing to share it with you, a fellow family member or individual with a disability. Your dilemma as a listener is that you are not providing professional services. Your primary responsibility is to safeguard the privacy of the requestor. On the rare occasion that you believe a serious problem or question exists and you cannot persuade the family or individual to discuss it with professionals, consult the Sharing Our Strengths Coordinator about what should be done.



### Confidentiality Statement

- Employees and volunteers of SOS will not disclose information about participating individuals or families, other volunteers or employees to anyone outside the program without the individual's prior consent.
- Information shall not be disclosed within the organization except on a need-to-know basis. This includes any identifying information concerning current, past or prospective mentors, requestors, families, other volunteers and staff.
- Mentors will not discuss SOS participants with others. Mentors must avoid mentioning names or discussing specific details that could easily be identified to a particular person or family. If necessary, mentors can discuss a specific person or situation with the SOS staff.

- The mentor will hold in confidence everything the referred person tells them, unless specific permission is given by the referred person to share the information with others.



### FAQ

#### Why is my requestor not calling me back?

Often, people are in crisis. Continue to leave messages, try calling at different times, or send an e-mail if provided. If it seems excessive, contact support staff toll free, 1-800-444-0821.

#### What if I don't know the answer to their question(s)?

Be honest. People appreciate being told, "I don't know". Refer them to Missouri Family-to-Family Disability & Health Resource center toll free at 1-800-444-0821, or via e-mail at [moddrc@umkc.edu](mailto:moddrc@umkc.edu).

#### When is the mentoring over?

When you accept the match a time frame may be provided. The natural flow of information and frequency of calls will slow down. Ask a requestor if they need anything else at the end of that time (5-8 weeks for a typical match). If they don't have further needs, let them know that they can contact you or SOS if they think of anything else. It is okay to stay in touch or end contact at the end of the match.

## Contact Log For Mentors

Please complete this form **each** time you contact a requestor. This is a tool for your use at home.

Date you were given match: \_\_\_\_\_ Date of first contact: \_\_\_\_\_

First Contact made by: \_\_\_\_\_ Phone \_\_\_\_\_ E-mail \_\_\_\_\_ Both

Length of phone call: \_\_\_\_\_ minutes                  Length of E-mail: \_\_\_\_\_ paragraphs

Name of person seeking support: \_\_\_\_\_

Spouse's Name: \_\_\_\_\_

Phone#: (\_\_\_\_\_) \_\_\_\_\_ E-mail address \_\_\_\_\_

### **Name, Age, Gender and Diagnosis of Family Member(s) with a Diagnosis:**

1. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

Diagnosis: \_\_\_\_\_

2. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

Diagnosis: \_\_\_\_\_

3. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

Diagnosis: \_\_\_\_\_

### **Sibling(s) Ages and Genders:**

1. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

2. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

3. Name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: Female or Male

### **Second Contact:**

Date: \_\_\_\_\_ Phone: \_\_\_\_\_ Minutes: \_\_\_\_\_ E-mail: \_\_\_\_\_ Paragraphs: \_\_\_\_\_

### **Third Contact:**

Date: \_\_\_\_\_ Phone: \_\_\_\_\_ Minutes: \_\_\_\_\_ E-mail: \_\_\_\_\_ Paragraphs: \_\_\_\_\_

### **Fourth Contact:**

Date: \_\_\_\_\_ Phone: \_\_\_\_\_ Minutes: \_\_\_\_\_ E-mail: \_\_\_\_\_ Paragraphs: \_\_\_\_\_

***Continue on back of this sheet***

## Contact Log For Mentors

### Situation/reason for contact:

- Share your experiences
- Be POSITIVE, but realistic
- LISTEN
- Support and Encourage
- Empower

### Notes:

### Type of information requested:

- Check your resource guide
- Need more info-call SOS staff

### Notes:

### Before you hang up, arrange day/time for next call:

- End on a positive note
- Suggest a get-together, if you'd like

### Notes: