

Family Advocacy Skills Training

A Handbook for Family Advocates



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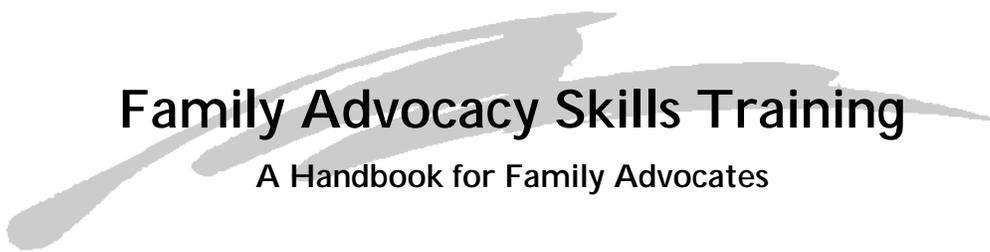
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The authors would like to thank all the people who helped develop this book. Survivors, their families who participated in FAST training classes, and family members and other professionals who reviewed the materials have all contributed to make this a program that addresses the needs of families dealing with the many changes and challenges when a family member's life is altered by brain injury. Some of those people are:

Joan and Bob Brown
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Examples used in this handbook are a combination of real people and fictional stories. Pseudonyms have been used throughout the book. Stories and examples are used to directly and clearly illustrate concepts in the text. Because real life rarely works out so easily, the examples may seem simplistic. Please understand that the stories are there to help clarify the rest of the text. Although your situations may be different, and more or less challenging, the concepts still can help.

Getting to know you

“Getting to know you, getting to know all about you...”
Rogers & Hamerstein

Goal for this chapter: To provide an overview of critical skills that families need to effectively manage services for a survivor.

What this book is about

You are probably reading this handbook because someone you care about has a brain injury. This handbook presents skills that can help you find, collect and organize information. It helps you step back and look at your situation now and ask what changes you would like to see. It then helps you put together a plan to make those changes. And finally, it helps you look ahead to the future by building a plan for the survivor and your family.

You probably already have many of these skills described in this handbook. This handbook helps you apply these skills and improve them. They are presented in logical order since each skill builds upon previous ones. The handbook is organized by chapters that coincide with training sessions for families. You may wish to form a group with other families to enhance your learning experience. Here is what is covered in each chapter:

1 Pre-session

Looking at the past, present, and future helps identify where you are and where you want to be. Learning to share resources and insights with others helps give a fresh start to the challenges of helping a person with a brain injury.

2 Who is ___?

The skill taught in this chapter is to make a complete list of all relevant information about the person with a brain injury. Then the “big list” is broken down to essential information needed by someone to resolve an immediate issue, problem or concern.

3 Goals, Hopes, and Dreams

Setting goals that work is the first step toward receiving better services. This chapter guides you through a goal-setting process that involves the person with the brain injury as well as others involved. After defining the goals, you may find there are too many things to do all at once. This skill helps prioritize the goals and set an action plan for success.

4 Refining the Plan

With an action plan in place, you can find information, resources, and support to help you reach your goals.

5 Partners in Progress

Working WITH service providers (as opposed to fighting them) gives the best results in the long run. The advocacy and communication skills in this chapter help you team up with professionals to successfully reach your family's goals.

6 How do I Know if this is Working?

Sometimes we run so fast and so far that we lose sight of where we were going. The skill in this chapter helps you focus on where you are, and if you are making progress toward your goals.

Although you may be using this handbook individually, it was designed for use in a workshop setting. In the first session, you will meet new people and share information about who you are and your situation. Sharing this information makes it possible to support each other and make the most progress possible. By working together and sharing what we each have learned, we will make the most of our time together.

Ready for action!

Am I ready for this? This question may be circulating in your head right now. Most of us probably don't *feel* ready to take on something so new and different. The reality is, most of us *will* be able to learn new skills and practice the ones we already know. We can become better advocates all the time. It isn't like you aren't acting as an advocate already! These skills are designed to make your job as an advocate easier and more effective.

One thing to remember, though, is that these skills are not right for everyone at all times. If the trauma of an accident is very fresh or if your family member is in life-threatening crisis, this may not be the right time to take on something new. Likewise, if your family is in crisis because of conflicts among family members or divorce or other loss is recent and unresolved, other forms of support or therapy may be more helpful at this time.

Of course, emotions are a normal part of everyday life, and living with brain injury is likely to bring more emotions to the surface. That alone doesn't need to stand in the way of participating in the FAST training. However, if those emotions are so strong they interfere with daily activities, this training may need to wait. Many support groups and other services specialize in helping people move through strong emotions. When those feelings no longer interfere with daily activities, you may then find the FAST training to be the right next step. In any case, you will probably find that some of the skills will be useful immediately, while others may come in handy later on.

Conclusion

When a family experiences the trauma of brain injury, you can bet that life will never be the same. As one individual with a brain injury says, "I used to be a geranium, but now I'm a petunia. I just want to be the best petunia I can be." Hopefully the skills presented in the following chapters will help you and your family be the best you can be.

Who is ____?

"The life which is not examined is not worth living."

Plato

Goals for this chapter: To describe how the survivor has changed since the brain injury, and to talk with different "audiences" in a clear and concise manner.

Where do you start?

Have you ever been in a situation where you begin to tell your problem to someone and things just seem to get worse? The situation may start out well, but after a few minutes, the person seems to stop paying attention. He or she cuts you off or interrupts and may even start telling YOU what the problem is before you have finished explaining. You may feel frustrated, unheard, and maybe angry. The "solution" suggested doesn't work, and you feel like you have wasted a lot of time or money for something that wasn't helpful.

This happens a lot, and it happens to all kinds of people and with all kinds of professionals. In this chapter, you will learn how to avoid this experience by replacing it with a more effective approach that works better for everyone.

Most of us have limited time. For example, a person may have several appointments in one day, or a professional may be seeing numerous clients back-to-back. When this is the case, you need to get the most accomplished in the time available. This is usually the case with any professional you encounter. You need to be very efficient when you communicate.

By now, you may have already had several bad experiences with professionals. This is a good time to start over. With the tools in this chapter and the rest of the handbook, families have found that their interactions with professionals have gone much more smoothly. Families get better results by working efficiently with professionals toward a common goal, rather than working against each other.

This first skill involves compiling a complete list of all relevant information about the person with a brain injury. Then the “big list” is broken down to essential information a particular person needs to resolve the immediate issue.

The Big List

This skill is like taking a snapshot of the survivor. The snapshot captures the survivor’s abilities and strengths, difficulties and needs, and changes since the injury. Professionals have many formal tests to gather information. They are the experts in their field. The family’s experience with the survivor is just as important as any formal evaluation by an expert. You are the expert about your family. Whether the survivor is your spouse, parent, sibling, son or daughter, you know this person better than anyone.

Your relationship with the survivor is unique. You have a tremendous advantage as a family member. You knew the survivor before the injury. You know what medical care and rehabilitation therapies the survivor has received. You know how the survivor has changed since the brain injury. No one else has your experience and perspective. Look at it as a partnership. Each person contributes from their expertise.

Describe the survivor

Family members become very knowledgeable about brain injury over time. By sharing this information, you can help others understand the survivor. Families need to constantly educate others about what it means to have a brain injury and how it has affected the survivor. The difficult part is organizing what you know into a quick summary for others less familiar with the survivor and less experienced with the consequences of brain injury.

Organize your knowledge and experience with the survivor by using the following checklist. Take into consideration that each survivor is different. Each will be affected differently by the changes in these lists. For instance... a married working husband who is the main family wage earner will have different problems and concerns than a younger single adult, mother, or retired older adult.



About the injury...

- how long ago was the survivor injured
- how was the survivor hurt
- how serious was the injury
- was the survivor in a coma
- how long did the coma last
- did the survivor have other injuries
- how long was the hospital stay
- was the survivor in a rehabilitation program?
- Did the survivor receive PT?, OT?, Counseling?

Describe the survivor now...including changes in

- physical abilities
- energy and fatigue
- speech and language
- vision
- personality
- hearing
- appearance
- behavior
- judgment

Describe how the survivor thinks and learns now, including changes in...

- attention
- concentration
- memory
- organization
- planning
- reasoning
- problem-solving

Describe how the injury has affected the survivor emotionally, including changes in...

- confidence
- temper and irritability
- awareness of others
- social skills
- alcohol or drug use

Describe how the injury has affected the survivor's ability to get along with others, including...

- friendships
- family relationships
- personal relationships
- sexual comments or actions
- employer relationships

Describe how you help the survivor, including...

- reminding and memory aids
- suggesting problem solving strategies
- organizing and planning tips
- making decisions
- cueing strategies
- developing safety and emergency plans
- arranging rest periods
- employing written and verbal communication
- changing behaviors
- listening techniques

Describe how the injury has affected the survivor's ability to...

- work
- participate in recreational/leisure activities
- earn a living
- have friends or close relationships
- live independently
- travel in the community



What is Critical?

What you have just done is to create the BIG LIST. This comprehensive list tells everything and is important because it includes all the details that may be useful at some time or other. When you talk to a particular person (a professional, a friend, an acquaintance), you don't need to share the BIG LIST. Instead, you need a brief summary that gives the most important information that person needs at that time.

Think of this as painting a verbal picture or snapshot of the survivor. Try asking yourself, what are the three most important things that I want this person to know? Reducing this to a two-minute description forces you to prioritize what is most important. The ability to quickly and clearly describe the survivor is a valuable skill that you can use repeatedly in meetings, interviews and discussions. The content will change, but the skill remains the same.



Putting the skill into action

In conversations with professionals, as well as friends, you can use this skill to describe the survivor and identify your concerns. Consider the following examples.

To a family friend:

Spouse – This is what happened and how it has affected my husband.

Robert had a severe brain injury 8 months ago when he was in a car crash. He was in a coma for 4 days. After 2 weeks in the hospital, he had 5 weeks of in-patient rehabilitation.

He has learned how to walk again, but he still uses a cane. Even though he wears glasses, he doesn't see objects unless they are right in front of him, so he can't drive anymore. The biggest difficulties are with his short-term memory and fatigue. Even his speech becomes slurred when he is tired. It takes him a lot longer to do simple things that he used to take for granted, like getting dressed in the morning or writing a letter. We used to be a lot more social, playing cards,

going out dancing with friends, but with his memory problems and his physical limitations, those are out.

There were times when he was feeling pretty low and even questioned whether it was worth living like this. He always had a sense of humor and that's helped him pull through some of the rough times. Unfortunately, people often don't get his particular sense of humor, it's a little strange.

Now he doesn't look disabled, but that makes it harder for people to understand that his thinking has changed. Everything requires more effort and he needs more time to make any decision. What's most frustrating for him is when people treat him as though he's stupid. He can do it, but he needs cues and extra time.

To a teacher at the beginning of the school year:

Parent - This is what happened and how it has affected my son.

Patrick had a brain injury last year when he hit a tree while skiing. At first we thought he would be paralyzed because he injured his spinal cord as well as his brain. Now it seems ironic that what first worried us the most was his physical injuries and whether he would be able to walk again. He got back the use of his arms and upper body, but his legs are very weak and he has a lot of spasticity. He uses a wheelchair, although inside the classroom he uses a cane for short distances.

His unpredictable behavior and mood swings are really difficult to handle. When he's frustrated or overloaded by too much noise or activity, he just blows up. He hasn't hurt anyone, but he can be very loud and intimidating. We've learned that he does better if we reduce his frustration by keeping his routine as structured and consistent as possible. But any major change is really difficult for him – and for those around him.

Mentally, he has changed too. His memory isn't too bad, but learning new things can be frustrating for him. He needs lots of practice. We also found that he learns best in the morning, before he gets tired.

To a new landlord:

Sibling –

Six months ago my sister was jogging and was hit by a car. Although she's made a pretty good physical recovery, she's just not the same. She was only in the hospital for five days, so people think it wasn't that serious. She tried to go back to college and is still hoping to finish but it's really slow. At least until she goes back to school she'll be home a lot. Even with a tutor, everything is just much harder now. If you looked at her, you wouldn't think that anything was wrong.

But when she talks, people think she's retarded. She talks slowly and sometimes has trouble finding the word that she wants. She also talks in a monotone voice and it's softer so sometimes it's hard to hear her, especially if others are talking. She can read but it takes her a lot longer to understand it. She still gets headaches and is really tired, so she may not hear someone knocking on the door. There's no way she can hold down a job and go to school too, like she did before. She has money in her trust to pay the rent, but sometimes she doesn't remember to pay it. It just takes reminding her.



Concise Description

The previous examples illustrate how a brief but accurate description can help the listener not only understand who the survivor is, but start to figure out what help is needed.

A concise description will be most effective if you tailor it to the person and the situation. Make sure you give all the important details for THIS situation, but leave out extra information that this person doesn't really need. The examples above take only two or three minutes. If you remember to include only what the person needs to know at this time, you can convey most of the important information in very little time.

The benefits of this approach are 1) the person quickly understands your situation and your needs, 2) less time is wasted, and 3) the survivor may get needed help.

Notes:

Description Worksheet

Imagine that the survivor just got a new referral to see a specialist about medications for better control of seizures. Cross out all the statements below that the new doctor probably doesn't need to treat the survivor. (Some statements are clearly necessary; some are obviously unnecessary. Some are more vague. Have fun!)

1. Jean's accident happened three years ago.
2. The car she was driving was hit on the driver's side by a truck.
3. She was in a coma for three days.
4. Her passenger wasn't hurt at all.
5. She made progress really fast, mentally that first year.
6. Jean's dog's name is Sparky.
7. The second year, she still progressed, just not as fast.
8. Physically, she got over the worst of it in the first six months.
9. Her seizures started about a year after the accident.
10. Her short-term memory is really bad now.
11. She took a class at the community college last year, but dropped.
12. The seizures seem to be getting worse this year.
13. When she has them, her little brother gets frightened.
14. I was scared too, at first, but I've gotten used to them now.
15. They seem to happen more when she is physically active.
16. She gets really tired, ever since the accident.
17. She used to get tired when she was little, too.
18. Here is a list of medications she currently takes.
19. Her regular physician is Dr. Jones.
20. We don't know of any drug allergies.

Please see the last page of this chapter for suggested answers!

Educating others

People who are unfamiliar with the consequences of brain injury often have inaccurate information. Families need to continually educate others about brain injury in order to get the support and understanding needed by survivors. Making fun of people with disabilities, avoiding them because of embarrassment, or pitying them because of their limitations – these reactions are based on ignorance. Attitudes can change through information and experience.

Keeping records and tracking information

By keeping a short written record of the dates, places and persons involved in the survivor's care, families can copy it for anyone needing this information. This is a shortcut to avoid redoing the same paperwork with every change. The following pages can be used to organize all the information you have about the survivor and their injury. You may wish to make a copy and put it in a notebook with other important related papers, or even type it into your computer. The important part is that you have all the information in one place that you can easily access.



Medical and Rehabilitation Summary. (please copy on separate pages)

Survivor's Name:

Address

Telephone

1. Injury

Date of injury

Cause of Injury

Describe all injuries

Length of coma

Date returned home after injury

Current condition

Medications

Special Equipment

Seizure History

Supervision/assistance needed

2. Medical care and rehabilitation

Days/Months

Dates

Hospitalized at

In-patient Rehabilitation at

Other Hospitals

3. People involved in medical care and rehabilitation

Hospital

Telephone

Family has reports?

Primary Doctor

Neurologist or Neurosurgeon

Head Nurse

Physical Therapist

Occupational Therapist

Speech/Language Therapist

Social Worker/Discharge Planner

Others

Rehabilitation Program

Primary Doctor

Head Nurse

Physical Therapist

Occupational Therapist

Speech/Language Therapist

Social Worker/Discharge Planner

Psychologist/Neuropsychologist

Others

Out-Patient Services

Physical Therapist

Occupational Therapist

Speech/Language Therapist

Psychologist/Neuropsychologist

Social Worker

Other

Community Agencies

Home Health/Visiting Nurse

Vocational Rehabilitation

Counseling

Other

Answers to the Description Worksheet

1. Jean's accident happened three years ago.
2. The car she was driving was hit on the driver's side by a truck.
(*)
3. She was in a coma for three days.
4. ~~Her passenger wasn't hurt at all.~~
5. She made progress really fast at first, mentally, for about one year. (*)
6. ~~Jean's dog's name is Sparky.~~
7. The second year, she still progressed, just not as fast. (*)
8. Physically, she got over the worst of it in the first 6 months. (*)
9. Her seizures started about a year after the accident.
10. ~~Her short term memory is really bad now.~~
11. ~~She took a class at the community college last year, but dropped it.~~
12. The seizures seem to be getting worse this year.
13. ~~When she has them, her little brother gets frightened.~~
14. ~~I was scared too, at first, but I've gotten used to them now.~~
15. They seem to happen more when she is physically active.
16. She gets really tired, ever since the accident. (*)
17. ~~She used to get tired when she was little, too.~~
18. Here is a list of medications she currently takes.
19. Her regular physician is Dr. Jones.
20. We don't know of any drug allergies.

(*) Some of these may or may not be important to the physician. When in doubt, let the professional decide if he or she has enough information. You can always give more information if necessary.

Goals, Hopes and Dreams

If you don't know where you are going, you might wind up someplace else.

Yogi Berra

Goal of this chapter: to help your family member set goals and identify strategies to reach those goals.

Once you have identified where you are, you're ready to figure out where you want to go. Quality of life is just as important after a brain injury as it was before. That is why this chapter helps people not only with goals, but also with hopes and dreams.

In this chapter, you'll learn how to work with your survivor to set goals and identify strategies to reach those goals. Setting goals that work is the first step toward receiving better services. This is probably the hardest part in learning to advocate for your family member: identifying specifically what will help the survivor be more successful and satisfied in life. This chapter helps you with this challenge.

Teamwork

Most of us need a little help figuring out what our goals are. We may talk to trusted friends, clergy, family members, or professionals to help us identify goals and steps to reach them.

Many families dealing with the challenges of brain injury find that involving others in the goal-setting process is critical. Often other family members, friends, or professionals have a different perspective on the survivor's life and can shed new light on the situation. In this chapter, you'll learn about how to involve others in the goal-setting process.



Where do we start?

The idea of “setting goals” can be overwhelming. Where do you start? You may be thinking... “Nothing is working for us right now—our son’s goal is to get his life back!” There may be so many pieces of your family member’s life that aren’t going well, that it’s hard to know where to start.

In the next section, you’ll learn about a process to help you focus and choose where to begin. The goal-setting process that is described will help you think creatively and systematically. With your survivor and anyone else you choose to invite, you can use this process to make an overwhelming challenge seem a little more manageable.

Making a MAP

The goal-setting process, called MAPs, (for Making Action Plans) is designed to be used in a group discussion. MAPs helps the survivor identify goals as well as barriers to reaching those goals. MAPs then helps the survivor form a plan for getting around or overcoming the barriers.

The most important thing about the MAPs is that it’s flexible. You can use it alone, with one other person, or with a group. You can follow the steps exactly, or modify them to better meet your needs.

Here’s the basic idea. You and the survivor sit down and decide whom you want to involve in a discussion about the survivor’s goals, hopes and dreams. Next, you invite these people to your home (or some other comfortable place) to meet for 1-2 hours. At the meeting, your discussion follows specific steps which allows you to identify goals, challenges to meeting those goals, and strategies for overcoming those challenges. What you and the survivor end up with is a “map” for how to proceed.

It sounds simple and it really is. It takes a little work up front and you may need some help running the meeting...but overall, families have found this approach really works. It can open the door to thinking creatively about getting services, finding support, and making the often difficult path of brain injury a little easier to navigate.

The Nuts and Bolts of MAPping

Many meetings are frustrating to attend. They often have no clear purpose, go on longer than necessary, and are dominated by several people. People may leave feeling like they haven't accomplished anything. A MAPs meeting is designed to help a group avoid these problems. Using the MAPs process, group members set clear goals and come up with specific plans for reaching them. The survivor takes the lead in this discussion whenever possible.

Decide Who Should Come

At a minimum, the group will include the survivor and you. Who else you invite is up to you.

Start by asking the survivor who should participate. You might want to make a list of possible invitees and ask the survivor's opinion of the list. Regardless of how the list is created, the survivor should make the final decision about who comes. If the survivor doesn't trust or care for someone who attends, the process probably won't work very well.

Some families find that a small group works best—for example, the survivor, a parent, and a professional. Others find that having a few more people is helpful. The great thing about the MAPs process is that it can be used with any size group.



Team members can include:

Survivor

The survivor must participate in the meeting. Without this involvement, the survivor will have minimal interest in any plans that are created. Suggestions for involving survivors are included later in this chapter.

Family members

Usually family members are the driving force behind the MAPs meeting. Although it's possible for a parent, spouse, or sibling to be the meeting facilitator, it's usually best to find someone who's a little less involved in the survivor's day-to-day life to run the meeting. This allows family members to participate fully and may reduce some of the emotional tension that sometimes surfaces.

Educators

If the survivor is enrolled in any kind of school or coursework, there may be a special teacher or staff person who would be a nice addition to

the group. Many school personnel know about a variety of community resources that may be helpful.

Community Members

Sometimes parents or survivors involve a support person or advocate. Community representatives (such as from a church or a service organization), or paid professionals (such as rehabilitation staff or agency representative) can contribute insights about how the survivor functions in community settings and may be able to offer resources at the strategies stage.

Friends

Whether to include friends of the survivor should be left entirely up to the survivor. Be sure the survivor understands that the process will cover challenges as well as strengths. Some survivors are uncomfortable discussing their difficulties with peers present

Role of the facilitator

As the facilitator, you have several important roles:

- To keep the process moving (everyone's time is valuable, including your own). If you keep meetings to the agreed length, people are more likely to feel positive about the meeting.
- To ensure that everyone gets a chance to present their perspective.
- To ensure that the dominant perspective is the survivor's.
- To encourage action on steps that help the survivor get closer to reaching goals.

Notes:

Prepare for the MAPs Meeting

If you are well prepared for the MAPs meeting, it is likely to be smooth and productive. Preparing for the meeting involves the following steps:

Talk with the survivor

It's important that the survivor understand the MAPs process. Explain what will happen at the meeting. Many survivors like to prepare for the meeting by completing a goal sheet like the one on p.31. This helps them get their thoughts organized for the MAPs meeting.

Schedule the meeting

Find a time that works for most of the people you want to invite.

Give or send the invitation

When you ask people to be involved, give them an idea of what to expect. For example, "We're having a gathering to talk about James—what he wants for his life, and how we can help him get there. We'd like you to come because you seem to care a lot about James,

and we think you probably have some good ideas."

Get materials ready

An important part of the MAPs meeting is recording everyone's responses so that the group can track the discussion. It is also helpful to have a written record. Colorful markers and a large flip chart, or sheets of paper taped to the wall or white board, allow the group to follow along easily. Have drinks and snacks available.

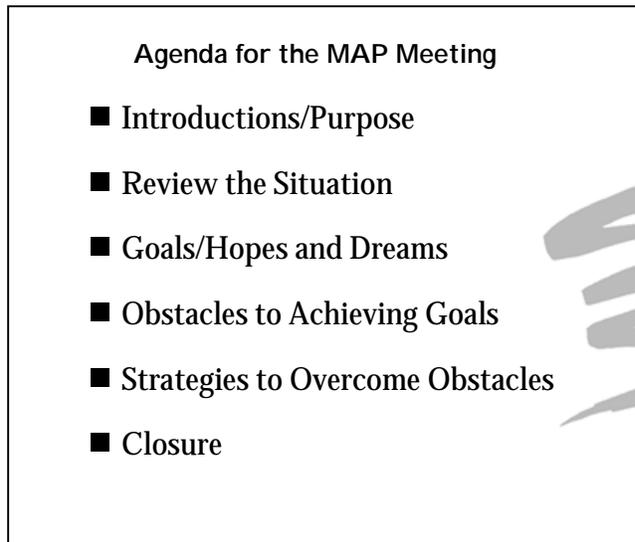
Decide who should facilitate the meeting

It is helpful to have someone (other than a family member or the survivor) lead the discussion and record comments on the flip chart during the session. The facilitator keeps the discussion moving along.



Conduct the MAP Meeting

Using brightly colored pens for recording, the group answers a series of questions designed to help create a specific action plan. Because the agenda is flexible and tailored to the survivor, it is easy to modify. The following section outlines important points for the facilitator. You may want to copy it and give it to whomever is leading the meeting.



1st agenda item - Introductions/Purpose

Ask everyone to introduce themselves and explain their connections with the survivor. Following introductions, go over the following points:

Explain MAPs: a goal-setting process to help the survivor become more successful and independent.

- **State the goals of meeting:**
 - to work together to help the survivor identify personal goals
 - to plan ways to help the survivor accomplish them
- **Give an overview** of what the meeting will be like:
 - how long
 - what happens after this meeting (the group may decide to meet again to follow up on ideas that are generated)

- **Emphasize that everyone is a valued member** of the group and is encouraged to participate.

Note: Although everyone present should be encouraged to contribute, it is important to pay particular attention to the survivor's involvement. You can do this by checking with the survivor frequently to monitor understanding of what is being said and whether the survivor agrees with the information that is being presented. The survivor has veto power over everything written by the recorder.

- **Explain brainstorming procedures:** all responses are accepted without judgment. Tell everyone that it's OK to dream and be unrealistic.

2nd agenda item - Review the Survivor's Situation

In Chapter 2, you described in great detail everything you knew about the survivor's injury. The MAPs process also begins with a description of the survivor, ALL framed in a positive and affirming tone. This process helps participants start with a shared picture of the survivor.

Begin with a short brainstorming session (about five minutes) about the qualities and characteristics of the survivor. Keep the comments positive now, challenges will come out later. For instance, if someone suggests that the survivor is "stubborn", reframe the comment as "persistent", or "determined", or another word that accurately describes the person in a positive way.

- **Write all the comments** on a sheet of paper using different colors, if you like. Pictures are also fun and keep the mood positive.



This begins as a brainstorming session. Make sure everyone knows what brainstorming means. All ideas are welcome and the conversation stays positive (problems with the goals will be addressed in the next section). The only person with veto power is the survivor.

Always begin with the survivor's hopes and dreams. Check in frequently to make sure that hopes and dreams and goals mentioned by others are shared by the survivor. The group can remind the survivor of goals mentioned or bring up activities the survivor has enjoyed that might point toward interest in a future goal.

- **Do not list goals that do not interest the survivor.** Sometimes a survivor may be reluctant to admit to sharing a dream that someone else has mentioned because it seems too distant. Remind the group that this is an opportunity to picture the ideal and list the goal along with more attainable ones.

*I've always wanted
to be somebody,
but I see now I
should have been
more specific.*
Lily Tomlin

- **Try to generate both long and short-term goals.**
- **Prioritize which goals are important to work on right now.** Once all the obstacles have been listed, have the group select which goals/obstacles they want to start with. Begin with the survivor, but encourage everyone to discuss why other items might deserve priority. For example: deadlines are approaching, some goals must be reached before others can be attained, etc. Goals that are lower in priority can be addressed later.



4th agenda item - Obstacles to Achieving Goals

The group now looks at the prioritized goals one by one and determines what is preventing the survivor from reaching each goal. Obstacles may have many sources—such as the survivor’s learning challenges, finances, lack of knowledge of services, etc. The facilitator’s main role is to clarify what the specific obstacles are without getting bogged down.

- **It is important to avoid jumping ahead to strategies before going through each of the steps.** It is especially tempting for the group to address one obstacle at a time instead of listing all the obstacles first. Try to stay focused on obstacles until all are listed for at least one goal. Depending on how much time is remaining, the group may want to move to strategies after listing the obstacles for the top priority goal, then go back and list obstacles for goal 2, etc.
- **Sometimes inadequate information can be an obstacle.** For example, the group might list “not sure how to find out if Joe will ever be able to drive” as an obstacle. In some cases, “missing information” may be a key obstacle to the survivor.

5th agenda item - Strategies to Overcome Obstacles

The group now brainstorms creative strategies to get around the obstacles they’ve come up with.

- **Before discussing strategies, review goals and obstacles and come to a consensus about any patterns.** What seems to be most important to the survivor? What obstacles need to be addressed most urgently? What obstacles are causing problems in more than one area? Most groups decide that it’s best to start with the most urgent obstacles (and goals).
- **List all ideas, no matter how improbable, expensive, idealistic, etc.** The brainstorming portion is fairly quick; it is important not to get attached to any one solution until all strategies are considered.



6th agenda item - Action Plan

Once everyone's ideas are listed, move to the action plan. The team, led by the survivor, selects several strategies to try, or comes up with a plan for getting additional information.

The action plan is formed
By listing three columns
on the flip chart:

Most of the tasks will be completed by the family and survivor. As you continue to network with others, you may find folks who can help you with some of the items.

Who	What	By when

- **Prioritize which goals are important to work on right now.** Have the group decide which goals or obstacles to start with once all the obstacles have been listed. Begin with the survivor, but encourage everyone to discuss why other goals might deserve priority: deadlines are approaching, some goals must be reached before others can be attained, etc. Goals that are lower in priority can be addressed later.
- **Remind the team** that even though some goals are listed as lower priorities, they are not dropping off the list. At the next meeting, progress toward goals can be reviewed. As goals are attained, new ones can be added.

7th agenda item - Closure

Help the group summarize the meeting. You might want to ask someone else to summarize. It is especially important to check that the survivor is comfortable with the action plan.

Encourage the group to give feedback or comment on how the meeting went. If people felt like the meeting went very well, they may want to get back together in a month or so to see how things are going.



Hold regular review meetings

It may not be necessary to reconvene everyone to review progress on the action plan. Only those who will help determine the next steps need to attend. The group's decisions and actions can be recorded on the Follow-up Action Plan.

Overview

Remind the group of the purpose of the meeting and what they hope to accomplish.

Review progress on the action plan

Team members first report on progress on putting strategies into action. Those present decide on the next steps to reach goals. Sometimes additional information will have been obtained that indicates a goal should be put on hold or that progress will be slow. You may suggest selecting a different or additional goal to work on in order to promote a sense of

success and accomplishment. Be sure the group and the survivor understand that the team is not giving up on the original goal.

If another goal is selected, review the obstacles, generate strategies if you have not already done so, and put together an action plan.

Update action plan

The new action plan has new strategies for the original goal as well as strategies for new goals.



Refining the Plan

“We can lick gravity, but sometimes the paperwork is overwhelming.”

Wernher von Braun

Goals for this chapter: To gather information, resources, and support in order to reach the survivor’s goals.

What this chapter is about

Now that you have identified goals, obstacles, and strategies; prioritized the goals; and used that information to decide on an action plan; it is time to find out specifically who to call or what information you need. A good thing to remember is that you are not alone. Nor are you the first person to be in this situation (although sometimes it may feel like it!) It may not seem obvious at first, but there is a lot of help available to you.

When you know the steps in your action plan, you will probably need information from various sources. You may also need referrals. And as you progress, you will probably need some support. The skill in this chapter is to refine your plan by 1) obtaining information, 2) obtaining referrals, and 3) finding support.

Gather Information

When you completed your action plan, you probably wrote down “get more information about...” for several of the action steps. What’s next? Figuring out what information you need and what to collect depends on what you want to do and what help is needed to get there.

Examples

Work

If the goal of the survivor is to find a job, then you need information about vocational rehabilitation services such as job counseling, writing a resume, interviewing, filling out applications, and accommodations on the job. Who in your community has hired people with disabilities? You will also need to know how the income from a job would affect disability benefits and medical coverage. The survivor also needs transportation to and from work.

Housing

If the survivor's goal is to find an apartment that is accessible and affordable, then you need information on special rental subsidies or mortgage programs for persons with disabilities. You need to know who is responsible for accommodations such as ramps and handrails. Will help with cooking, cleaning or physical care be needed and where can it be found?

Future planning

If parents are worried about who will look after the best interests of the survivor when they are deceased, then information is needed about estate planning, guardianship and conservatorship.

The effective information search

For many years, information about brain injury was scarce. What little information did exist was very hard to find. Since the mid 1980's, more and more information has become available, and access to it has gotten much easier. With increased funding toward research and development, and the increased availability of electronic aids, including the Internet, the amount of information can now seem overwhelming.

In order to gather the information you need without getting discouraged and frustrated, you need to plan well. The MAP process helped you identify specific goals and action steps, and allows you to narrow your search for information to a list of the most helpful and pertinent information. When you look for that information, use smart searching techniques to get the most out of your search.

Contact the national or local Brain Injury Association and ask for specific guidance. Inquire about specialized resource centers, like the Oregon Brain Injury Resource Network. You may also want to ask friends, professionals you know, support group participants, and others who understand your situation if they know about any of the information you need. By looking in the right places, you reduce the frustrations you may find by gathering too much information, or information that isn't that helpful.

Brain Injury Association, Inc. Family Helpline: 800-444-6443 Internet: www.biausa.org/

Notes:

Example 1

Spouse – This is how our family has been affected and what we need.

My husband used to be a sales manager for a real estate company that has 5 offices. After he used up all his sick leave at work, he resigned because he couldn't do his old job anymore. In fact, we don't know if he'll ever be able to work again. He didn't have a disability policy, so we're really worried about income. Our worst fear is that we will lose the house. I've gone back to work as an office manager, but I don't make the kind of money that my husband used to, so we have had to really scale back our expenses.

Our first priority is to find out if he is eligible for any disability benefits. Then we need to figure out if he can do some kind of work. We know he can't go back to his old job, but he's only 48 and there must be some kind of related work he could do. Even part time work would help our budget. But more than the money, he needs to work to get back some of his pride and sense of self-worth. It's sad to say that even though he had lots of business contacts, hardly anyone calls anymore. It's as though they don't know what to say to him and so it's easier to just avoid us.

We need to gather information on....

- his employer's disability policy
- applying for social security disability benefits
- finding a driver evaluation program
- determining if he is likely to work again in the future
- possible career transitions or related work areas
- a support group to reduce his isolation



Example 2

Parent - This is how our family has been affected and what we need.

My husband had a heart attack last month, and we are finally reaching the point where we don't think we can take care of our son at home any more. The doctor says my husband has to take it easy and I'm afraid that if he doesn't he'll have another attack. We've been managing so far with help 3 days a week from the visiting nurses, but that's just a short-term solution.

We're managing with the physical care, but it's my son behavior that really is most stressful for us. There's no way that my husband can get the rest that he needs when our son's behavior is so difficult to control. It's like living with a volcano that can erupt at any time. And our son has become even more difficult to manage since my husband's been sick.

Our son really needs a place to live in the community where he can be as independent as possible, but still get the physical help and management of his behaviors he needs. We know the move will be hard for him, but we'd rather do it now while we can help him adjust.

This health crisis of my husband's has made us to realize that time is passing. My husband had retired just 3 months before our son's injury and we had all kinds of plans. Now I don't know if we'll ever get to travel or just take some time for ourselves. I feel like I'm torn between what we want and what our son needs. Thinking about the future is really difficult, but I know we have to do it.

We need to gather information on....

- locations of group homes, supervised apartments, or supported living programs for our son
- the cost of these programs
- how to better handle his difficult behaviors
- back up plan for my son's care in case my husband is hospitalized again.
- guardianship
- revising our will and estate planning

Example 3

Sibling - This is how our family has been affected and what we need.

My brother and I still live in a house we bought together a couple years before he got hurt. I work as a computer programmer. We are both single and we had a pretty good time partying together. He was finishing up his master's degree through night classes and working days as a loan officer at the local bank.

I can tell it's getting to him, because all his friends have moved on – they're getting married and settling down and he's still trying to figure out how to put his life together again. I know he's been drinking while I'm at work because I find the bottles. The drinking is bad enough because the doctor warned him that it could trigger seizures. But I worry that he might use drugs again and that really scares me.

Now I have a chance for a really good promotion at work, but it means I will have to relocate. He can't afford to live in our house by himself. We used to split the mortgage, but I'll have to find another place if I move. He could live alone, but I don't see how he could afford it.

I'm really worried that he'll get really depressed living by himself if I make this move, but I have to look out for myself. What kind of social life can he have? He needs friends to do things with that interest him. But it could be really dangerous for him if he went back to drinking and partying.

We need to gather information on....

- substance abuse counseling programs
- support group for young adults
- health clubs to get him out of the house
- options for work
- advertising for a roommate to split expenses



What do the federal laws say and how can they help?

The programs described next are the main building blocks for services that are either funded or protected under federal legislation. Information is readily available from pamphlets and the internet.

Americans with Disabilities Act

Covers the rights of persons with disabilities for ...

- Public transportation
- Accessibility to buildings
- Hiring and firing on the job
- Civil rights of persons with disabilities

Suggested contacts include the state Department of Vocational Rehabilitation, Office for Disability Rights, and the Office for Social Security.

Income and Disability Benefits

- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- Medicaid
- Medicare
- Food Stamps

Suggested contacts include the Office for Social Security, Department of Public Welfare.

Housing

- Provides startup or partial funding for housing and rental subsidies for urban and rural communities. Includes...
- Elderly housing complexes
- Special units in HUD funded buildings for persons with disabilities
- Rental subsidies

Suggested contacts include state, regional or local Department of Housing, Department of Elder Affairs, Department of Consumer Affairs.

Figuring out the system

By identifying the key agencies in your state, you can gather information, learn how funding is directed and approved, what services are available, and how referrals are made. Programs or services for persons with brain injuries may be under the administration or umbrella of various state agencies since there is no state agency just for brain injury. For example, services might be available under the Department of Developmental Disabilities if the survivor meets the requirements for having a developmental disability. Likewise, a survivor who is abusing drugs or alcohol might find services through the Division of Substance Abuse. Or if depression is the underlying cause of the substance abuse, then the Department of Mental Health may be a resource. The list below includes state agencies or departments that serve survivors in some way...

- Developmental Disabilities
- Education
- Elder affairs
- Housing
- Medicaid
- Mental Health
- Mental Retardation
- Substance abuse
- Probation
- Public Health
- Public Welfare
- Social Services
- Vocational Rehabilitation

Many of these agencies or organizations will be listed in your local phone directory. If you have trouble finding local agencies, call your state Brain Injury Association or other disability associations.

When gathering information about services and programs, it is important to ask if the following affect eligibility:

- Current age of survivor
- Age when injured
- Town where survivor lives
- Income
- Employment
- Living situation
- Diagnosis or primary disability
- Secondary disability

Putting it in writing, the contact record

Keeping track of telephone calls, conversations and meetings, filing copies of reports and gathering brochures and handouts is very important to fitting the pieces of the puzzle together. A Contact Record helps you file and organize information as you speak with persons in programs, resources or agencies. You may use the example on the next page. Make as many copies as you need.



Contact Record

Date _____ Time _____

Person contacted _____

Title _____

Dept. _____

Address _____

Phone # (____) ____ - ____ extension _____

Questions to ask:

Information received:

Next step:

Creating a notebook and filing system to collect and organize information

Just as the survivor had a medical record in the hospital, families have found that it is important to develop a record at home for information. Too often, families don't ask questions if it's not important at the time. However, needs and situations change. As many families have commented, "Just when I think I've got everything figured out and in place, something changes and I have to start all over again. Now I collect everything as I go because I never know when I might need it." Organize and file what you collect in a three ring binder so you can find it when you need it. Suggested sections are:

- Medical care
- Rehabilitation
- Education
- Transportation
- Advocacy
- Recreation
- Vocational rehabilitation
- Housing
- Disability/financial benefits
- Insurance/Medical benefits
- Legal issues

Gather Referrals

Introduction

A referral is a pathway to a person or program for information or services. Family members have a lot to say about referrals – what help or services are needed, when they are needed, what is affordable or too costly, and whether help or services are located conveniently. Family members can also judge how effective referrals have been – what the results were and whether they were worth the time, effort and expense.

No matter how many titles or degrees the person you are referred to has, remember that you are still the expert on the survivor. You still have the most familiarity and experience with the survivor before and after the brain injury.

Often survivors are seen by many specialists and have lots of tests that result in thick files filled with technical reports. All of this is expensive, stressful and time consuming. Too often, families become frustrated with referrals when they have little to show in practical results and positive changes. To avoid this, consider asking the following questions in advance.

Questions about referrals

- Why does the survivor need to be referred to a specialist or program?
- When does this need to happen?
- What are the steps to make it happen?
- What will it cost and who will pay for it?
- What advance information will the person receiving the referral need?
- What results can I expect?
- What follow-up needs to be done?
- If we have this test (or evaluation, or conference), what difference will it make to our lives?

Some referrals require the involvement of a professional. For example, your physician must send a referral for you to have x-rays or lab work. Under some insurance plans, you need a referral from your primary care physician to see a specialist. However, there are many situations where you can refer yourself. For example, if the goal is to find a recreation program, then you can go check out the local YMCA or health club. If the goal is to get disability benefits, then you can refer yourself to the Social Security Administration. If the survivor wants to find work, then contact the vocational rehabilitation agency in your area.

Another valuable source of referrals can be found in TBI or other disability related support groups or with others who have been through a similar situation. By trial and error, others may have found providers who were particularly effective or others who were less satisfactory.



Sometimes you have a lot of choices for referrals; other times, options are limited. Choices can be affected by:

- Qualifications and experience
- Cost of services
- Location of services
- Available programs
- Waiting lists

Many families aren't sure where to start. What questions should you be asking and what should you be looking for? How do you figure out who can help you? How can you get what you need?



Referrals to professionals

Specialists who can explain a survivor's strengths and abilities, as well as difficulties or weaknesses, in understandable terms can be hard to find. It is the practical suggestions, when combined with the interpretation of tests and clinical information that can make a real difference in helping the survivor. Check that any professional that evaluates the survivor has experience with:

- survivors of brain injuries (at similar age level)
- severity of the survivor's injury
- survivor's current stage of recovery or time after injury.

For example, if the survivor had a severe brain injury five years ago then a referral to a sports medicine doctor who specializes in evaluating athletes with concussions might not be the best choice.

Familiarity with the services that you are seeking is also important. A neuropsychologist who only sees survivors during early in-patient rehabilitation for baseline evaluations might not be familiar with what information a vocational counselor needs for a work evaluation in the community.

Look for someone who...

- is familiar with the program or service that you are considering
- has experience with survivors in such programs
- knows the lingo used by the program

Finding the right person is often at least half the battle. Recommendations from others with similar experience and from persons working in that area are good places to start. The following can give you suggestions...

- national or state Brain Injury Association
- other survivors and family members
- professionals previously involved with the survivors and family

Some referrals require written applications, interviews, meetings, testing, report writing, or evaluations. Ask ahead of time to know what's required and ask how long it is going to take.

The results that you want from a referral can include...

Things...

such as a place to live, more money, insurance, transportation, home modifications

Plan with strategies and techniques for...

learning, controlling or changing behaviors, coping with changed abilities, compensatory strategies or cueing systems.

Services...

such as vocational rehabilitation, home health care, counseling, support group or driver training

Continuing with the three previous examples of family members, this is how referrals can be customized to meet the individual's needs.

Spouse whose husband wants to return to work–

These are the referrals needed for my husband to meet his goal of increasing his income, having transportation and working part-time.

We can refer ourselves to the...

- Social Security Administration about disability benefits
- Company that handles his employer's disability policy
- Support group run by the Brain Injury Association
- Dept. of Vocational Rehabilitation

We can ask his doctor to...

- refer him for a driver evaluation program at the rehabilitation hospital's out-patient dept.
- supply information about his medical history to document his disability.



Parent who is considering residential options for son...

I need referrals to...

- a neuropsychologist to learn how to manage behaviors at home.
- respite care program to reduce stress and provide temporary relief until residential care can be arranged or for emergency care in case father is hospitalized again.
- an attorney experienced in state and federal benefits for persons with disabilities, estate planning and guardianship.
- community programs that provide residential services.

Sibling who is relocating needs referrals for...

- support group of survivors
- substance abuse counseling program
- assessment of vocational options



Questions to ask before agreeing to the referral

Being an informed consumer means asking questions.

- What is your experience with survivors of brain injuries?
- Do you do any formal testing?
- How do you decide what tests to use?
- How will you explain results to the survivor?
- How will you share information with the family?
- Who will receive written reports?
- How long will this take?
- What follow-up will you do?
- What will this cost and what kind of payment do you accept?

As the family, you have important information and experience to share with any professional or program. You can use the information from the first two chapters, including:

- Your assessment of the survivor's strengths and needs
- Summary of medical and rehabilitation services
- Primary concerns about the survivor now
- Hopes and goals for the future

Notes:

Worksheet for Referrals

1. The GOAL that you want to work on is:

2. What referrals will help you reach this goal?

3. Describe the help, service or program that you are looking for from the referral.

4. WHEN does this need to happen? By a certain date/month/year?
Think about if the survivor has needs that require an immediate referral for services as soon as possible, or if a referral will help address long term needs in the future?

5. CHOOSING the right person
This involves matching a specialist or program's experience, style and location with the survivor's interests and needs. Consider the following when looking for a referral:
 - experience with the survivor's age group
 - experience with survivor's severity of brain injury
 - experience in
 - medical treatment
 - neuropsychology
 - specific therapy
 - vocational training
 - housing
 - recreation
 - home health care
 - peer support
 - rehabilitation
 - psychology
 - school/education
 - counseling
 - substance abuse
 - driver training
 - homemaking

e. observations of the survivor with friends

f. special interests, skills and talents of the survivor

g. brief summary of how the survivor has changed since the injury (use your verbal snapshot from the assessment skill)

You may be asked for copies of the following:

- medical records
- school reports
- work history
- insurance information
- financial information

Other information to provide:

Gather support

Like information and referrals, it takes some planning to get the support you need. Support can be very valuable, and indeed, may be what keeps you going while you work toward gathering the rest of what you need. The challenges of life with a brain injury can feel insurmountable at times. If you start feeling drained and depleted, these are signs that you are emotionally overloaded and may benefit from some kind of support.

Some people are comfortable asking others for support. Others may find it difficult, even humiliating, to ask for help. One important thing to remember is to keep a balanced attitude toward seeking support.

For example, if you ask the same people for support too often, or the issues you bring up seem too trivial to them, they may turn you away. Choose the issues you need help with carefully, and ask for help with just the issues that are appropriate with this person. It also helps others if you sometimes offer help to them as well. There is a good reason for the saying, "I'll scratch your back if you scratch mine"! For example, offering to be part of a family panel at a conference is a way of helping professionals.

On the other hand, if you don't ask for support, you may not receive the help you need. Just think, if someone came to you and asked you for support with a very difficult issue, wouldn't you want to help him or her? Many people consider helping others as an opportunity to do something good in the world. Why not give people a chance to contribute and give yourself the chance to get the help you need. Balance is the key.



Finding support

There are many places you can go for emotional support. Some sources are organized and accustomed to providing support to families with a survivor. Others are individuals who can be helpful, even though they may not know much about brain injury.

Support Groups

Many support groups already exist. You may find support in groups for family members of a person with a brain injury. There are also groups for survivors. Some groups focus on people with all types of disabilities, some only include specific diagnoses or conditions. They may meet weekly, monthly, or just as needed. A good way to find a group in your area is to call your state Brain Injury Association (BIA). If no support groups exist in your area, you can even start your own. The BIA may provide some assistance in starting a new group.

The Internet and Chat Rooms

With the growth of the Internet, there are many chat rooms and list-serves for survivors and families. This is another way to connect with people to reduce isolation, find others with common concerns, and provide support. Although people don't meet face to face, many families connect and communicate with others in this "cyber community".

There are also several web sites developed by or for survivors and family members that talk about common concerns and provide both support and information. A good place to start is the Brain Injury Association's web site at www.biausa.org
By exploring the links, you will find many resources.

Note: The last three letters of an Internet address provide information about the type of organization that provides the site. If the letters are **.com**, you can expect a commercial site, (one that probably has something to sell). Although more will become common soon, the following are commonly used now: **.edu** (education); **.net** (similar to **.com**); **.org** (usually a non-profit organization); and **.gov** (a federal, state, or local government entity).

Friends and Family

Of course, friends and family may be helpful. Sometimes they don't understand brain injury and they may be critical or impatient, but basically, parents, siblings, and spouses can and do provide a lot of emotional support when a person has a brain injury.

Counseling

Private counseling can help if your challenges are very difficult, or if you need an objective point of view to help you make good decisions. Family counseling can also help with the new family dynamics that are sure to surface when a person has a brain injury. Because issues for a person with a brain injury are often different than other problems, it is important to find a counselor who is familiar with TBI. Ask your support network for recommendations, and of course, ask the counselor.

Medical or Rehabilitation Facilities

If the survivor currently or recently received services from a medical or rehabilitation facility, especially one that specializes in brain injury, that facility may have some support groups or other support services available.



Conclusion

Basing your action plan on sound and acceptable goals is a good start. In order to make the most progress possible, it is important to find out what already exists and who can help you. The many sources now available will make gathering information much easier than it would have been five or ten years ago. Gathering referrals from people and professionals you trust may also reduce the amount of frustration you experience. Both these steps are well worth the time invested. Gathering emotional support is one way to take care of yourself. The support you find can sometimes provide you with the confidence and courage to continue on your journey.

Partners in Progress

We are all in this together, by ourselves.

Lily Tomlin

Goals for this chapter: To assertively ask for what you need, to negotiate effectively to get services, and to work collaboratively with professionals.

This chapter presents several skills that are helpful when working with professionals. After you have planned, set goals, determined action steps, and sought information and referrals, you often need to interact with professionals to get the services. The main sections of this chapter are about 1) assertiveness, 2) collaboration, and 3) negotiation.

Passive, Aggressive, or Assertive

Most of us have developed an approach for working with professionals. The approach we use may be described as passive, aggressive, or assertive. Of course, we don't always use only one way, and sometimes we change approaches based on the situation.

Some people have had success with being aggressive or passive. In certain instances, acting passive or aggressive is actually the most effective approach. But in the long run, we have found that the assertive approach provides the most consistently positive outcomes for families.

The PASSIVE approach

When using the passive approach, people often are:

Quiet
Timid
Vague
Inconsistent
Embarrassed

They:

Avert their eyes
Speak softly
Accept what the other person says
Avoid asking questions
Don't offer solutions

The AGGRESSIVE approach

When using the aggressive approach, people often are:

Loud
Demanding
Unreasonable
Rude or attacking
Disrespectful

They:

Don't listen
Interrupt the other person
Accuse
Blame

The ASSERTIVE approach

When using the assertive approach, people often are:

Attentive to the other person
Respectful
Clear
Consistent
Cooperative
Understanding
Reasonable

They:

Make eye contact
Listen before they talk
Ask questions
Make strong and clear statements
Accept responsibility where appropriate
Use "I" statements
Paraphrase and acknowledge the other person's comments
Offer solutions
Stay focused

The Five Elements of Assertiveness

1. Listen

Don't get distracted by personalities: Pay attention to what the person is saying. If you don't understand, ask questions to clarify. Focus on needs not complaints. Sometimes it helps to make notes, especially if the topic is complex.

2. Demonstrate that you understand

Check the accuracy of what you think the other person said. You might begin by saying "If I understand what you said," . . . Pay attention to the other person's reaction to what you say. If you didn't quite get it, ask more questions and check again.

3. Say what you think and feel

Because so many problems can arise because of even a slight miscommunication, it is important that you make sure the other person understands how you feel about the issue as well as what you are thinking about it at the moment. Remember to use “I statements”. For example, “I feel very frustrated right now.”, or, “I think my son can do more than one hour of therapy a day”.

4. Say specifically what you want to happen

If you have a reasonable, well thought out request that reflects clear goals and are within the abilities of everyone involved, a clear request should be either granted, or at least, be a starting place for negotiating what can be done. If your request is vague, confusion is more likely, and what one person is committing to may be completely different than what the other person thinks is the case. Frustration is almost sure to follow. To avoid this problem when suggesting a solution:

- Be concrete and specific
- Be realistic
- Include timelines

5. Consider the advantages and disadvantages of joint solutions

Perhaps the best solution would be the one that both parties develop together. If you see that the solution you presented just won't work, maybe together, you can develop one that will. Often, when both parties approach a problem as a team, the best solution will appear, one that neither party thought of individually!



The Collaborative Approach

There once were two farmers, next door neighbors, in a rural part of the state. One farmer raised sheep. The other farmer raised cattle. The fence between their farms was worn out and falling down.

Every time a sheep broke through the fence and ate in the cattle's field down to the bare ground, the cattle farmer got angry and would yell at the sheep farmer to fix the fence. Of course he would fix the fence (but not very well) and because he was angry, he took a long time and allowed the sheep eat a lot of the cattle's grass. This went on for many years.

Sometimes the cows would break through the fence and wander all over the sheep's field. Then the sheep farmer would yell at his neighbor to fix the fence. They were becoming enemies.

After several years of this going on, the farmers were pretty angry at one another, and the fence was the worst it had ever been. They finally decided to work *together* to rebuild the fence. The sheep and the cows had different fencing needs. The farmers talked about all this and decided on the kind of fence that would work for both farms. Together they bought materials and worked, side by side, replacing the rickety old fence.

They became friends again.

Collaborating with professionals is very similar to the two farmers. If you find yourself on opposite sides of the fence, you may not accomplish as much as you would like. If, however, you and the professional can solve the problem together, the results AND the process will be more beneficial for everyone.

Look at the situation from the other person's point of view

A technique used to prepare for a debate is to argue FOR the opposing side of the issue. This practice gives the debater a good idea about the arguments the other person might use. You can use this idea yourself when preparing for an appointment. Think about what the professional or agency staff might say. Consider what questions and concerns they may have. You might even want to write them down so you can go back

to the list when you prepare. When you actually talk with the person, you will have already thought about many of the issues, and you will have clear answers and strategies for dealing with problems. In your practice “discussions” remember to prepare answers that are respectful and clear.

Find an ally in the system

Many people find that they “click” better with certain people. They may be other professionals in the same office, or you may find them in other ways. The key is, when you find someone you work particularly well with, consider them as an “ally”. Sometimes the systems and red tape are so challenging we need an ally just to fill out the application forms. When you need to contact that agency again, you’ll know whom to call.

Be prepared

Sometimes, preparation for an important appointment or meeting will make the difference between success and disappointment. You will garner more respect from the person you are meeting with and waste little time. Good preparation will also make it easier to be assertive if necessary.

Do your homework

Remember to use the skill in Chapter 2, “Who is ___?”: Be prepared to give a brief yet complete description of your loved one, a description of the most important information for that particular professional. Also, as you think about the questions they may ask you, make a list of information you think they might need. You might be amazed how receptive professionals can be if you have all the needed information at your fingertips.

You may be thinking, how can I possibly do all this just to get ready for an appointment? It is true, this seems like more work in a day that is probably already full with activities and responsibilities. Consider this: it may take just 15 to 30 minutes for most appointments. And, if taking the time to prepare results in a shorter appointment or eliminates the need to go back or call back with information you have to look up at home, isn’t it worth the extra time? In addition, after you have your notebook organized (Chapter 2), and you have practiced this skill several times, you will spend even less time preparing, yet the results will still be substantial.

Define what you want

This can be tricky and requires that you be clear about what you expect. Make it clear what you need. The specialist or program can't be a mind reader and most survivors have many needs. The specialist or program needs to know what you expect just as you need to know what they offer. Sharing information during the referral process is a two way street. It's a bit like matchmaking. If the person or program can't meet your needs, it's better to find out in advance rather than after spending a lot of time, effort and money.

Write a proposal and be willing to negotiate

For some of the more complex or difficult appointments you have, you may need to actually write a proposal. This can be simple or complex, but will probably at least include a description of the current status and a request for assistance. Be specific about what the problem is and how the person can help. But just because the request is in writing doesn't mean you have to stick with it. The professional may suggest something different that may still be a good solution.

Negotiating

Need for negotiating

Sometimes, even after preparing well, practicing, presenting your case assertively, clearly stating requests, and being willing to negotiate, the best the agency offers is just not enough. This may be the time to step up the level of intensity, if you are confident that the agency could do better.



Steps in negotiating

There is no need to “use a canon when a pea-shooter will do”. Usually, the best way to progress is to take your case to the next highest level in the agency. This is a matter of seeking out the supervisor or other staff responsible for these kinds of issues. If you begin this process, **KEEP VERY DETAILED ACCURATE RECORDS** of what you experienced at the last stage. Sometimes, it really is necessary to continue up the bureaucratic ladder several times. The further you go, the more important written records become. Keep good notes, and keep them organized.

If an agency person tells you something you think sounds completely off, ask them to put it in writing, with the date and their name. If they aren't willing to do that, you have a good idea that their suggestion wouldn't hold up to their supervisor's inspection.

If the issue is with a doctor or other professional, get a second opinion or switch doctors. If your insurance or other payer won't pay for a second opinion, consider carefully if it is important enough to pay for it yourself. It may or may not be.

Make the appeal from a collaborative point of view

There is strength in numbers. It's much more effective to work **with** professionals than in opposition. Collaboration, or working together, means that each party brings valuable information and experience as they work toward a common goal. Most people who go into helping professions do so because they care about others and want to make a difference in their lives. Start by assuming that the professional you are talking to is a caring person.

Eye on the Outcome

Focus on the goals you have defined. Although the stakes are high and emotions can sometimes cloud the issues, the best results are likely to result if you keep the goal in sight. Getting sidetracked with personality clashes or disagreements about minor points can keep you from accomplishing the goals that you have worked so hard to set. If the discussion moves away from the goals, remind the other person what the goal is and why it is important.

Partners with a common goal

The most important part of this chapter is that when people work TOGETHER they can accomplish far more than if they work AGAINST each other. We have presented a few of the many techniques available to help achieve this goal of collaboration.



Notes:

How do I know if this is working?

Evaluate, improve, adjust. In these continual actions are the seeds of success.

Anonymous

Goal for this chapter: To evaluate progress on meeting your identified goals.

The reason you work so hard on developing the goals and action plan is to improve services for the survivor. On many levels that seems obvious. What may not appear quite as obvious, however, is the importance of revisiting the MAPs process periodically.

Revisiting the MAPs

By checking on the progress of each action step or goal, you can easily see which needs have been met and which have not (and why...) When you (and the survivor) have this information clearly laid out in front of you, it is much easier to refocus everyone's energy into the areas that are most important, based on the original or updated goals.

For example,

Jayme, a young man who recently graduated from high school, determined during the MAPs process that getting a job was a high priority for him. His action plan included contacting the Employment Division, the Vocational Rehabilitation Department, and two local employment agencies. His initial attempts to contact the Employment Division and Voc. Rehab. were stalled because Jayme didn't fill out the necessary paperwork. Contacting the employment agencies was easier, but yielded no referrals. Three months later, he still didn't have a job.

By revisiting the MAPs plan, Jayme and his parents identified where he got stuck and altered the plan to help Jayme increase his chances of success. They had Jayme contact his high school counselor (who was particularly helpful while Jayme was still in school) to see if she would be willing to help him fill out that paperwork. She *was* willing to help, and now, Jayme is back on track.

When to reevaluate

Revisit the MAPs plan every three to six months (depending on the scope of your goals). Because you have a clear record of what was decided, who was to do which item, and when it was to have been accomplished, it is pretty easy to identify which goals have been met. If the goals and action steps were very challenging, you may need to break them down to smaller steps. Remember, life is what happens every day, not something that we get to later. Small accomplishments are very important steps in achieving major goals.

Celebrate

Celebrate the accomplishments! When a goal has been met, congratulate yourself, family members, or others who have been helpful. For major goals, a party or other celebration may be called for. For smaller accomplishments, send a short thank-you note or another expression of your appreciation. And imagine how a thank-you *from the survivor* might touch the person who helped achieve a goal!

Barriers

If a goal has not been met, try to identify the barriers. Maybe the goal wasn't perceived as a high priority (Reprioritize or remove some less important goals from the list temporarily). Perhaps information or resources weren't available (make an alternate plan or brainstorm a list of contacts who may be able to guide you to the needed information). A professional may be slow to respond, or the bureaucracy may have been too confusing (troubleshoot: is there a lack of skills? motivation? is he or she overworked?)



The main focus is to keep things progressing. If you see where the barriers are, you have a better chance of overcoming them. It is understandable to become frustrated or angry about the lack of progress. Don't let that cause you to just throw your hands up and give up. Use that energy to plan to overcome the barriers so the process continues. And by celebrating the accomplishments (and there WILL be accomplishments) everyone involved will sense the momentum and perhaps be energized to tackle the next challenge.

A new plan

When you have “checked off” the goals that have been met, and have identified the barriers that have surfaced for the goals that have not yet been accomplished, it is time to develop a new action plan. Well, really, it is just a revision. There may be new goals, new barriers, and you will identify new strategies to overcome those barriers. You know how to do it, just make sure to write down all the steps. Remember, you will be looking back at THIS action plan in three to six months, and going through the process again.

Parents who chose residential program for son

Having our son move into a residential program was one of the hardest things for us to go through. We realized what pressure and tension we had been under when we finally got a good night's sleep and were no longer living from day to day, crisis to crisis. But I think a parent always feels some guilt over a decision like this. Especially during the first couple weeks when he insisted on leaving and coming home. Saying no was the hardest thing I ever did.

We revisited our MAPs plan with our son. I think it helped him to remember that he was frustrated with living with us, too. That helped all of us have the strength to stick with the plan. There were some barriers we didn't think of, though. We had to find ways to overcome them so he could begin to feel at home in his new place.

There is no doubt that my husband and I have some sense of normalcy in our lives again. We will always have this sadness and think of what might have been had the accident not happened, but we are finally recognizing our limits. And, we have some times for ourselves again. That's important to use, especially at our age.

Sibling who relocated

I get so angry with my brother sometimes and then other times I feel really bad for him. It'd be a lot easier if he showed a little gratitude sometimes. Now I've learned not to expect so much of him. But I've also learned that it's okay to tell him when he screws up.

He did manage to get through a community college class last semester and that was a big step. When we

talked through his MAPs plan to see the progress, we realized that it will take him a lot longer than we first thought. So we adjusted the plan. Now he's got an appointment set up with the voc rehab people so he's making progress. It's slow, but I'm starting to recognize that I can only push him so far and after that, it's up to him. He's slowly figuring out how to put his life back together – it's just really different and progress is slow. Whenever he gets off track (or gets upset with me because I'm telling him what to do) we bring out the plan. It helps him remember that he has these goals, these things that are important to him. It seems to help get him back on track.

Spouse whose husband returned to work

When something like this happens, it forces you to reevaluate what's important. Before, we led a pretty fast paced life, did a lot of traveling and entertaining, but my husband worked so hard that we really didn't spend much time together.

We knew how to make plans before the accident, what we didn't have to rely on then was going over the plans to see if we were meeting our goals. Now we have discovered that seeing the goals in front of us, being able to check them off, then planning the next steps are vital to accomplishing the things that we consider important. And the interesting thing is that what is important to us has changed!

When our daughter graduated from high school last week, all I could think of was how grateful we all were that he was there with us at the ceremony. I realize that our life will never be the same again, and we may still have to sell the house and I don't know what kind of job I'll be able to find, but that old saying "at least we have each other" really means something to me now.



Evaluating programs and professionals

When you identified what prevented accomplishing a goal, you may have found a professional who was the barrier. Occasionally that happens. This section will help you deal with that situation if it arises. Criteria that families have used to evaluate the effectiveness of a program or professional include knowledge, clinical skills, and communication.

There are five major areas of knowledge that families feel are important. They are:

- basic anatomy of the brain
- changes in physical, cognitive, social, behavioral and communicative skills after a brain injury
- resources in community
- state and federal programs for persons with disabilities
- laws protecting rights of persons with disabilities

The skills that will be needed vary for each survivor but may include:

- medical management
- behavioral analysis
- rehabilitation therapies
- compensatory strategies
- nursing care
- adaptive devices
- daily care
- special education



Any or all of the above information can be learned on the job or by education and special training. However, it is the interpersonal skills that are less easily taught that so often make a difference in the quality of the relationship between a caregiver, professional, survivor and family. Persons can have the knowledge and skills listed above, but be ineffective if they do not have the following:

- trust of survivor
- belief in survivor's potential for growth and improvement
- common goals with the survivor
- respect for the family

Communication with the survivor and family can “make or break” the relationship. Professionals come and go, but families remain the constant in the life of the survivor. Therefore, the following qualities are criteria that families have listed as important when they evaluate the effectiveness of any caregiver or professional:

- communication skills – verbal and written
- ability to explain information clearly and understandably
- flexibility
- interest in learning from family's experience
- availability to meet or talk with family
- openness to new ideas
- willingness to go “the extra mile”

As you prepare to give feedback to program staff, consider the following questions to organize your evaluation:

- How does the survivor feel about the program or professional? (and why)?
- How did this program or professional communicate and share information?
- How well were the special needs of the survivor met?
- What was the most important benefit for the survivor?
- How was the family included?
- What was the most important benefit for the family?
- What was the program or professional's greatest strength and weakness?
- Did the program or professional deliver what was expected? If not, why not and what can you do about it?
- Are there any changes that you would recommend to make the program more effective?
- Would you use this program or professional again?

Conclusion

Most people would not choose to have a brain injury, or to live with someone who does. It is important to remember that an estimated 5.3 million Americans currently live with disabilities resulting from brain injury (Centers for Disease Control and Prevention): you are not alone. Life before and after a brain injury look very different, both for the individual, and for the entire family. Life doesn't have to be "worse", but it will be different. The fact is that any one of us, including the people we sometimes have trouble with, may suddenly have to deal very personally with the tremendous challenge of brain injury. By using the skills in this book, we hope you can make the best of your life and the lives of those around you.