1 Section Five

- *Individual Family Advocacy*
- *Systems Change Advocacy*
- *Systems Change Study and Review Questions*
Section 5: Individual Family Advocacy

Definition: Advocacy – an advocate is one who supports or speaks in favor of another, one who pleads for another.

Family Resource Facilitator – an advocate is one who acts as a wise advisor; a teacher or a coach.

Purpose: This section is designed to provide you with knowledge and skills to assist a family in the following ways:
   a. Teach families how to do problem solving (see curriculum)
   b. Teach families how to be advocates for their child/family with neighbors, relatives and others

Participant Objectives:

- Demonstrate effective individual family advocacy skills outlined above.

Who does not have problems? Sometimes problems pile on top of other unresolved problems. Sometimes, every person in our lives appears to have serious problems at the same time. Many times we have turned to someone else to help us sort things out. We don’t want THEM to solve the problem, we just need to communicate with someone who will reflect back and assist us in arriving at our own solution.

Family Resource Facilitation is about helping families find their own solutions to problems. How is this done? At times problem solving is appropriate. It is helpful to check with the families you are working with to determine if:

1) talking is sufficient or
2) they are looking for answers.

Some problems have no easy solution. You can however, provide support to an overwhelmed parent. The following steps outline the path to take:

Steps to Effective Individual Family Advocacy:

- Put things in writing and ask for things in writing.
• Speak your mind. Do not apologize.
• Know who is responsible.
• Set deadlines.
• Repeat your point or request.
• Keep the discussion focused on the issue.
• Have the facts and keep them in front of you.
• Cooperate with others.

REMEMBER: Your role in problem solving is to ASSIST OTHER PARENTS in finding a personal solution to the problem.

Knowing what questions to ask is often a first step to becoming a better advocate. The most important questions to address are:

1. What is the problem? Identify the problem. Use active listening and ask how, what and why questions to help the speaker articulate the issue.

2. Why do think the problem exists? This helps the parent bring out underlying issues and enables the person to provide a personal perspective on the problem.

3. What have you tried? This helps determine what has already been done.

4. Has it worked? What happens when you say (or do) that? This is an important follow-up question to step 3.

5. What are some other ways of solving the problem? Drawing on what has been discussed in steps 3 and 4, you can help parents search for new, creative solutions.

Active listening will allow parents to “try on” different solutions to the problem.

Use the Problem Solving Process

1. Identify the problem and gather information.

2. Make a list of possible solutions to the problem.

3. Identify the person or agency that has the power to resolve the problem.
4. Understand the chain of command.

5. Identify the steps to take and set time lines.

Using the problem solving process read the following story and answer the questions listed below.

A mother calls. She has an 8 year old boy who is diagnosed with ADHD. She states that he has difficulty sleeping at night and it is difficult to wake him up for school in the morning. While he is cooperative for the most part at home, this is the third time this week she has been called to come get him from school. He does have an IEP and has been diagnosed with a learning disability in reading. Recently his pediatrician prescribed Ritalin.

Identify the problem?

Where can information be found to help identify the problem?

What are some possible solutions to this problem?

What individual(s) have the power to resolve the problem?

What should be your first step assisting the family as an advocate in this situation?

**SEE SUPPLEMENTAL – ACTIVITIES**

Activity No. 9 – Role Play #1A & #1B

With a partner decide who will play the roles of parent and mentor.

Remember, you will each have a turn. Play out each scenario. After each role play, review with each other what worked and what didn’t.

Exchange roles.

What did you learn?

What were the challenges?

**TIPS ON GETTING A FAMILY READY FOR A MEETING:**

a. Make sure that the child’s folder is up to date.
b. Keep critical documentation from the past in the current folder.
c. Write down questions or concerns that you have…make copies for the professional, as well.
d. Ask someone to come with you to the meeting to take notes, help keep the focus…provide an extra set of ears.
e. Keep data that gives a sample of the area of concern: such as number of days with incomplete assignments in school; numbers of temper tantrums, dates and times.
f. Bring the child’s folder or binder with you to the meeting.
Advocacy for Systems Change

Definition: One who speaks for or on behalf of another.

Purpose: Each person in this training is an advocate for change: for ourselves, our children and families, others, systems and services in our community and state. The following resource is an invaluable tool for us as we grow in our FRF roles. It contains information at your fingertips about how to, what to, and who to.

Participant Objectives:

- Demonstrate knowledge of the process of systems change advocacy.
- Define three advocacy arenas to participate in.

Sponsored by the Coalition for Utah’s Families. Some wording is changed for Legislative Coalition for People with Disabilities use.

Tools and resources to help you advocate for the health and human needs of Utah’s families

Learn how to be a 10 minute Advocate

You can make a difference…. Advocacy is already part of your life. Most of us do it every day. Your experiences speaking up for your child in school, the neighbor or friend in need, etc. will enable you to become a very effective advocate for the needs of Utah’s families.

WHY YOU?

No one else can speak for you. Everyone needs to participate, or we truly do not have a democratic government, one that is operated “by the people, for the people.”

There are four basic steps to becoming involved in the legislative advocacy process. They are:
Step 1 – Choosing & learning about your issues

First, you must identify what issues of concern you want to influence. There are too many different areas for you to attempt to advocate for them all effectively. It can be anything – school system, streetlights, potholes, the waiting list, etc. What concerns YOU about your family, neighborhood, school, community, state and/or country?

Is the issue a personal issue between you and one other person, a community issue, a state agency issue, or will it take legislation to make a difference? The legislature is the hardest place to make a change. At what level can you solve your issue? ___________________

What are YOUR issues or concerns?

Family______________________________________________________________

Education__________________________________________________________

Employment__________________________________________________________

Health______________________________________________________________

Housing______________________________________________________________

Personal______________________________________________________________

Transportation________________________________________________________

Other________________________________________________________________

Now that you know what you want to advocate for you need to TELL YOUR OWN STORY to policy makers. They have never experienced what your needs are. While you do not need to know everything, you must be able to answer the question “why?” Your position should be heard. Learn more about your issue; resources are available such as existing advocacy groups, newspapers, providers of services, etc.

You can reach the USILC by calling the office at (801) 463-1592, Kris Fawson at (801) 243-1055 or by e-mail kfawson@comcast.net. You can reach Joyce Dolcourt, Chair of LCPD, at (801) 718-3013 or by email to: joyce@xmission.com.

Step 2: Identify the Decision Makers
Call your local county clerk. Ask for the names of the legislators that represent people at your address:

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<th>County</th>
<th>Phone Numbers</th>
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<tr>
<td>Beaver</td>
<td>435-438-6463</td>
</tr>
<tr>
<td>Box Elder</td>
<td>435-734-2031</td>
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<tr>
<td>Cache</td>
<td>435-716-7150</td>
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<tr>
<td>Carbon</td>
<td>435-636-3200</td>
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<tr>
<td>Daggett</td>
<td>435-784-3154</td>
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<tr>
<td>Davis</td>
<td>801-451-3213</td>
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<td>Duchesne</td>
<td>435-738-2435</td>
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<tr>
<td>Emery</td>
<td>435-381-5106</td>
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<tr>
<td>Garfield</td>
<td>435-676-8826</td>
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<td>Grand</td>
<td>435-259-1322</td>
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<td>Iron</td>
<td>435-477-8340</td>
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<td>Juab</td>
<td>435-623-0271</td>
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<td>Kane</td>
<td>435-644-2458</td>
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<td>Millard</td>
<td>435-743-6223</td>
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<tr>
<td>Morgan</td>
<td>801-829-6811</td>
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<tr>
<td>Piute</td>
<td>435-577-2840</td>
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<tr>
<td>Rich</td>
<td>435-793-2415</td>
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<tr>
<td>Salt Lake</td>
<td>801-468-3427</td>
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<tr>
<td>San Juan</td>
<td>435-587-3223</td>
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<tr>
<td>Sanpete</td>
<td>435-835-2131</td>
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<tr>
<td>Sevier</td>
<td>435-896-9262</td>
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<tr>
<td>Summit</td>
<td>435-336-4451</td>
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<tr>
<td>Tooele</td>
<td>435-843-3148</td>
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<tr>
<td>Uintah</td>
<td>435-781-5360</td>
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<tr>
<td>Utah</td>
<td>801-370-8128</td>
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<td>Wasatch</td>
<td>435-654-3211</td>
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<tr>
<td>Washington</td>
<td>435-634-5712</td>
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<td>Wayne</td>
<td>435-836-2731</td>
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<td>Weber</td>
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If you can get access to the internet, you can also get this information at

- [www.le.utah.gov](http://www.le.utah.gov)
- [www.votesmart.org](http://www.votesmart.org)

**Step 3 – Understand the Legislative Process**

To understand how to influence potential legislation, you must first discover how the legislative process works. The State Legislature is responsible for making and changing state laws, as well as setting funding levels for the executive branch of government (the state budget).

There are two processes that take place:

1. **The Appropriations Process decides the state budget** and sets the funding levels for state programs, for example: funding for the waiting list, education, health care, Medicaid, housing, deaf and blind services, employment, etc. This is where your advocacy will take place if you have budget concerns.

2. **The Bill Process creates or changes state statute** and creates new programs, for example: creating an assistive technology program, the lemon law, changing statute of how funding is distributed to school districts, etc.

Advocacy begins when YOU recognize a need to improve a program, create a new program or change state statute. Begin by talking to advocacy groups and getting others involved. Next you want to talk to state agency directors. Finally you take your issue(s) to legislators.

If your issue goes through the Appropriations Process you want to find out which Legislative Appropriations Committee would be discussing your issue. Contact the members of that committee. The appropriation committees that work consistently with disability issues are:

**Health and Human Services** – Early Health Services, Health Care including Medicaid, Substance Abuse and Mental Health, and Services for People with Disabilities.

**Higher Education**
Public Education – Education, Schools for the Deaf and Blind, Rehabilitation including Independent Living, Services for the Blind and Visually Impaired, Services for the Deaf & Hard of Hearing, Vocational Rehabilitation.

If you are creating or changing state statute you must find a legislator who can support your idea or “carry the bill”. This idea then becomes a bill which needs to pass through the legislative process in order to become law. A bill will be heard and voted on seven times before it becomes a law.

Remember: YOUR VOICE IS IMPORTANT in the legislative process. As few as seven to ten calls can make a big difference.

Gold Rules of Advocacy:
1. Be fair and respectful toward public officials.
2. Avoid cynicism. Government may be faulty, but so is very profession.
4. Be friendly. Don’t contact public officials only when you want their help.
5. Be reasonable. Recognize that there are legitimate differences of opinion.
7. Be charitable. The failure of public officials to do what you wanted may be your responsibility if you have not done a good job in preparing your case.
8. Be constructive. You don’t like to be scolded, pestered or preached to – and neither do they.
9. Be realistic and persistent. Remember that controversial legislation and regulation usually result in a compromise not wholly satisfactory to anyone contending party.
10. Be practical. Recognize that each lawmaker has commitments and that a certain amount of vote-trading goes on in all legislatures.
12. Be informed. Do your homework. The mere fact that you want a public official to adopt your position won’t be enough.
13. Be loyal and trustworthy. Never leave officials out on a limb by changing your position after they have publicly taken the position that you have urged upon them.
14. Be discreet. Participation in discussions about lawmakers being “bought” or “paid off” is worse than useless.
15. Be generous. Remember that in success everyone can claim credit. Thank policymakers for their positive acts at least as often as you inquire why they went wrong.
16. Be visionary. Especially when it comes to the political process, there is seldom an absolute defeat. A loss with one member may lead to finding a better champion elsewhere.


Step 4 – Communicating Your Views

It only takes 10 minutes!
Should you call, testify in person, e-mail, visit or write policymakers?

It depends on your schedule and what resources you have. If possible, avoid depending on e-mail. Personal visits can make a big difference if you can find the time. No matter what form you use follow these guidelines:

- Always identify yourself by name and address. Perhaps the most important thing you can say about yourself is, “I am a voter in your district”.
- Be brief, informed, and polite.
- Identify the issue, budget item or bill you want to talk about. Don’t assume they know about it – they have so much to deal with!
- State your purpose for calling and what your position is. Give one or more reasons for your position. It is almost always a good idea to speak from personal experience.
- Tell your own story.
- Always thank them for their time.

Calling
Policymakers pay attention when citizens take the trouble to call and convey their views. Call just before upcoming votes in committee, on the floor, or late in the session. Avoid calling on Sunday, or on Monday evenings.

House: (801) 538-1029 (800) 662-3367
Senate: (801) 538-1035 (877) 585-8824
Governor: (801) 538-1000

Writing/E-mail
Letters are good early in the session. E-mail is best during the session.
Write to: Senator / Representative ________ (insert name of your legislator)
Utah State Capitol
Salt Lake City, Utah 84114

Fax and E-mail
House Fax: Republicans – (801) 538-1098 Democrats – (801) 538-9505
Senate Fax: Republicans – (801) 538-1035 Democrats – (801) 538-1449

Visiting
Call ahead and make an appointment. Be on time. Be brief – 10-15 minutes. Respect their schedules. Take a one-page outline – a short written fact sheet – to remind them about your visit and concerns.
Frequently Asked Questions

How do I know if my issue is a bill or an appropriation (budget item)?
Bills passed by the Legislature will change, delete or add to the laws of the State. The state budget is passed as a bill too, but the process is different. During the General Session appropriations sub-committees put together the pieces of the overall budget, setting the levels and kinds of programs that are available through the various state agencies.

Where can I get legislative information?
Most legislative information can be found on the internet at:
http://www.le.utah.gov

Where can I get a copy of a bill?
Use the web-based service described above or visit the Bill Room at the Legislature in the basement of the Capitol. Copies are 10 cents a page.

How can I follow what’s happening to a bill?
- Read the newspaper. The major dailies run updates each day.
- Call Legislative Information at these numbers:
  - Senate (801) 538-1035
  - House (801) 538-1029
- Check the LCPD Website: www.lcpdutoh.org
- Check the Legislative Website:
  - http://www.le.utah.gov and use the tracking service.
**Sharing Your Story**

By Michael Newman
Recovery and Resiliency Peer Program Manager
Certified Peer Support Specialist and Family Resource Facilitator

**DEFINITION:** Sharing your and your families’ recovery story is an important element in providing peer support services. This “lived experience” is one of the most distinct features that separate peer support from traditional clinical services.

**Purpose:** To provide Family Resource Facilitators with knowledge and information about the role and importance of self-disclosure when working with families and professionals.

**Participant Objectives:**

- Understand the appropriate time and place for self-disclosure.
- Understand the importance of sharing their story in a positive way showing progress towards recovery and resilience.
- Identify relevant elements of their own recovery story.
- Practice telling their own recovery story.

**Why is self-disclosure so important?**

Sharing your story with others creates a *safe* environment for the families and clients you are working with. Doing it in an appropriate manner shows you are *empathetic* to their unique situation, since you have been through difficult circumstances yourself.

Most importantly, it inspires *hope* with those you are sharing with, who may feel optimistic about their or their families’ futures while you are working with them. It also creates a level of trust between you and your families that also can benefit the other relationships they have with professionals assisting them.
Sharing your story brings a certain level of humility that individuals in the behavioral healthcare system do not always experience from providers. When you meet someone at “their level,” it takes away a lot of the power differential that can exist between individuals and clinicians, administrators, and other professionals. This not only makes people feel more comfortable with you, it is also trauma-informed.

Sharing these personal and private parts of our lives can lead to feeling vulnerable, especially in the beginning. However, as you continue to practice and see how your experience can impact lives, it will help you realize the valuable tool that a recovery story may be.

**Illness vs. Recovery Stories**

A good rule of thumb when sharing your story is to focus on where you and your family member may have been, while not dwelling too much on negative situations, but rather focusing on how you have managed to progress to a healthy level of recovery in you and your families’ lives. Say what you need to connect with someone, but remember to stay as positive as you can.

An all too common situation is when individuals share about difficult circumstances, often traumatic, that go into specific details and end up possibly triggering individuals of whom you are trying to assist. Knowing anything about your families’ situation may help you avoid certain details and possibly triggering any individual.

*Is your story focused on your tragedy or your transformation?*

**What are the components of an effective recovery story?**

It is helpful to remember you do not need to have the exact same disability, whether yours or your family member’s, as the family you are working with in order to connect with someone. It’s more of a, “I have been in a similar situation or place” mentality. For this reason, diagnoses do not always need to be shared, unless it is something you feel appropriate for the situation, or are comfortable with. Only share what you are comfortable with in your story. You may become more comfortable the more you share and will gradually find out what key points in your story are most effective.

It is important to **be concise** when you share and not “ramble on.” Remember, when you are meeting with a family member or family it’s *not about you!* Along these lines, we never want to “one up” individuals and take away their experiences or the impact they may have on this individual.

    An example of this would be:

    Client shares, “My child was in the hospital for two weeks, it was devastating to our family.”
    FRF shares, “Two weeks can be hard, but my son was in the hospital for 8 months! It was terrible!”
From this statement, the FRF did not appropriately validate their client; rather the statement comes across as invalidating, and put the focus on themselves and their situation, when the focus should always be on your client.

Similarly, using active listening skills, we should always be listening more than we are talking. It can be tempting to jump in and share your life story, but we should only share what is necessary.

Some questions to ask yourself would be:

- How did I (and my family) overcome difficult obstacles?
- What helped during my “darkest days”?
- What do I do to stay in recovery?
- What is the value of my experiences?
- What strengths have I developed?
- How do (or did) I stay optimistic?
- If I was in a difficult spot, what would I ask someone that has overcome something similar?

**Who Do We Share Our Story With?**

There are many appropriate settings to share your story in. Depending on the situation, you may share different details and have varied lengths to your story so that it may be relevant for your audience.

We can share our story:

- With families, family members, and clients we work with
- In an advocacy role (e.g., with school, healthcare, and governmental administrations)
- In groups
- With co-workers
- With the media
- With anyone, anywhere when the time is right!

The more we share our story, the more we help to break down the walls of stigma and educate people on the difficulties, joys, experience, and perspective of having, or being close to individuals with various disabilities.

**The Risks of Sharing Your Story**

There are a few risks to consider when sharing your story:

- It may put the focus more on yourself than on your client.
- You may come across as your way is the only pathway to recovery.
- It is possible to share too much and possibly trigger another individual.
- You are sharing a piece of yourself, know that at times you may feel vulnerable from sharing personal information. It takes time to develop a story that is effective in various settings, appropriate, and something you are comfortable doing (everyone is different).
ACTIVITY: Role Play

1. Write down the key points of your recovery story that would be important to highlight in sharing your recovery story.

2. Pair up into groups of two and take turns sharing a brief version of your recovery stories.

3. Share your recovery story with the group, and we’ll all give and receive feedback.