



NATIONAL FEDERATION OF FAMILIES

For Children's Mental Health



A Workbook on Data- Informed and Family-Driven Decision Making: Evidence is Co- Pilot

This workbook is intended for use by family leaders. It is the result of an eight-part web-based training by the same title provided by the National Federation of Families for Children's Mental Health.

**National Federation of Families for
Children's Mental Health**
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INTRODUCTION

This workbook is intended for family leaders in the children's mental health arena. Others may find the material useful, but will have to make adaptations for the language that is specific to children's mental health.

We hope the contents will be useful both in workshop or training sessions as well as for those individuals trying to improve their knowledge and skills on their own. We encourage use of any parts of this workbook, but request that you give acknowledge and give credit to the National Federation of Families for Children's Mental Health.

We welcome feedback on this workbook and are especially interested to know how useful people may find it and what specific improvements should be made. Please send your comments to the Director of Training and Evaluation by Email to eslaton@ffcmh.org, by fax to 240-403-1909, or by telephone to 240-403-1901.

The credibility of the family movement depends on our ability to bring forth accurate, reliable and valid information.

CHAPTER ONE: IMPROVED DECISION MAKING

This first workbook chapter offers a basic justification for families to participate in decisions in a very thoughtful way and guidelines for effective decision making. It includes the following topics.

- Points in the Decision-Making Process
- Three Requirements in Effective Decision Making
- Three Tactics for Improving Decision Making

POINTS IN THE DECISION MAKING PROCESS

There are literally thousands of decision points that go into building and sustaining programs. Doing it right has everything to do with helping children, youth and families achieve the outcomes they desire and living the fullest lives they can. As family leaders, we have a primary decision making role in designing, building, evaluating, and sustaining successful programs. Our expertise comes from the experiences of raising our own child with his or her personal experience of mental, emotional, or behavioral challenges. Our expertise may also come from long term membership in the community and hence be about the culture of our community, the socio-economic strengths and weaknesses of our community, the history of our community. Or, our expertise may come from having transferred into the community from one with strategies that could inform this community. And, too often, our expertise includes an intimate working knowledge of other child, youth and family services. That expertise can and should inform local, state and community progress. That expertise can

and should inform many of those thousands of decision points along the journey of transforming children’s mental health.

So, when there is a possibility of participating in a decision making process, it behooves us to make the best of it.

THREE REQUIREMENTS IN EFFECTIVE DECISION-MAKING

(1) BE CONNECTED TO A LARGE NETWORK

Strive to be connected and informed by a large network of culturally, ethnically, socio-economically, structurally (and so on) diverse families in your community so that you can speak from our collective experience and not just your own (NOTE: engaging a single family member is usually tokenism; too often the tendency is to select a family member who is “most like” the rest of the system's governance committee, advisory board, or evaluation team members - and who is not connected to the network of families - to reduce the potential for conflict)

(2) BE A GREAT LISTENER

Aim to thoroughly understand the others’ points of views before formulating a response (NOTE: If you are not willing to listen to and consider other’s perspectives, how can you expect them to listen to or consider yours?)

(3) BE WELL INFORMED BY DATA

While we want any decision to be informed by the data that explains the problem and supports the direction we take to address it (making decisions), we looked to see what data we might find about how collaborative decision making, such as that that can occur in communities, actually works. Does it

make a difference in the outcomes? Does it make for better child and family well-being? Frankly, is it worth our time?

ACTIVITY 1.1 SELF ASSESSMENT ON DECISION MAKING PROCESSES

Conduct a self-assessment on where your strengths and weaknesses are in the three requirement areas of the decision making process. Where do you need to improve?		
CONNECTED	GREAT LISTENER	INFORMED BY DATA
Strengths	Strengths	Strengths
Weaknesses	Weaknesses	Weaknesses

THREE TACTICS FOR IMPROVING DECISION MAKING

(1) BE COLLABORATIVE

Being collaborative does not simply mean working together. It means working together effectively. Working together effectively includes listening carefully to others and suspending biases. Refrain from engaging in narrow thinking; be open to new ideas and tactics. Always analyze the pros and cons of the situation; while it can be tempting, don't get hung up on one

word or phrase, focus on the bigger picture you are aiming to accomplish.

(2) BE ACCOUNTABLE

Be willing to be held accountable for the results. This is a process, and it must come with credibility and stability. Take responsibility for this process, with strengths and weaknesses included.

(3) STAY FOCUSED

In order to truly be effective, we must stay focused on what we are doing and why we are participating. Have a clear vision and keep what you are trying to accomplish in the forefront. Losing the focus will compromise all other efforts, once people are unclear of what the bigger picture is, assumptions and biases come into play, and the vision is lost.

ACTIVITY 1.2: HOW ARE YOUR SKILLS AND ABILITIES ON THE THREE MAJOR TACTICS?

Conduct a self-assessment on where your strengths and weaknesses are in the tactics for improving decision making.		
COLLABORATIVE	ACCOUNTABLE	FOCUSED
Strengths	Strengths	Strengths
Weaknesses	Weaknesses	Weaknesses

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CHAPTER TWO: WHAT IS DATA-INFORMED, FAMILY-DRIVEN DECISION MAKING?

This chapter dives into defining key terms and exploring where and how one participates in decision making.

- Defining data-informed and family-driven
- Finding your sphere of influence and understanding how decisions are made within it
- Exploring the concepts of smart decision making

DEFINING DATA-INFORMED AND FAMILY-DRIVEN

In the title and throughout this workbook the phrases *data-informed* and *family-driven* are used frequently. In the context of this workbook as well as the context of our work as leaders in the transformation of the children’s mental health system, the definitions for these terms are as follows.

FAMILY-DRIVEN is a term first used in *Achieving the Promise: Transforming Mental Health Care in America*, the final report of the New Freedom Commission on Mental Health published in 2003. Subsequently, the federal Substance Abuse and Mental Health Services Administration contracted with the National Federation of Families for Children’s Mental Health (National Federation) to engage in an inclusive process of defining the term. Today, the working definition is that families *have a primary decision making role in the care of their own child, as well as the policies and procedures governing care for all the children in their community, state, tribe or territory.*

This includes:

- *Choosing supports, services and providers*
- *Setting goals*
- *Designing and implementing programs*

- *Monitoring outcomes*
- *Partnering in funding decisions*
- *Determining the effectiveness of all efforts to promote the mental health and wellbeing of children and youth*

DATA-INFORMED is a term that seems to have become more popular in venues where the use of evaluation, research, and data is being encouraged. The National Federation supports and encourages this focus, understanding that developing our positions on various issues requires something far more thorough and systematic than going on opinions, assumptions, or ideas of just a few people. Indeed, the credibility of the family movement depends on our ability to bring forth accurate, reliable and valid information. Data are collections of information produced from systematic processes that include many sources and apply scientific methods. The underlying premise is simple. The more informed by data, the better the decision.

FINDING YOUR SPHERE OF INFLUENCE AND UNDERSTANDING HOW DECISIONS ARE MADE WITHIN IT

As a family leader, where do you make a difference? Who listens when you speak? Where is it that your input has an impact on decisions that are made? In other words, what is your *sphere of influence*? Take a moment to think about your sphere of influence and in what areas you may have a voice in decisions that are being made about the children’s mental health system?

Family leaders may have influence in the following areas.

- **Local Family-Run Organizations**

- Governance committees
- Community Meetings
- Parent Teacher Associations
- Support groups
- Peer to Peer Programs
- Advisory Boards

Take a few minutes and complete Activity 2.1.

ACTIVITY 2.1 WHERE IS YOUR SPHERE OF INFLUENCE?

List the groups or arenas in which you think you have influence.
(Examples are in the list above.)

Where do you think you have the most influence and why?

Recall one important group decision that has been influenced by your input. List the reasons you believe your input was utilized in that instance.

Now that you have completed the exercise to identify your particular sphere of influence, think about how decisions get made there. In preparing for a decision, who listens well? Who talks the most? Does everyone get a chance to be heard? Do people ask clarifying questions and seek to understand one another's perspectives? What kind of information is considered? Does the information go beyond personal opinions and preconceived ideas? Is there truly thoughtful discourse prior to a decision being made? What is the final decision making process? Is there one person who has the final say? Is there a vote? These are all important considerations as you prepare to participate in the best way.

EXPLORING WHAT GOES INTO SMART DECISION MAKING

KNOW AND ACKNOWLEDGE YOUR OWN ASSUMPTIONS

One of the biggest barriers to smart decision making can be our personal collection of assumptions. In fact, many people will go so far as to claim they have no assumptions when reality is that we all have them. Our view of the world, the things we believe to be true, are naturally laid upon what we observe and the results can become something far from the truth. Sometimes the assumptions that get in our way are seemingly small.

An example of an assumption is that I think/believe/assume red high top converse shoes are worn by youth. So, when I spot red high top converse shoes in a crowd of people, I assume they are on a young person, before I look up to see who is actually wearing them.

Decisions made without clear examination of underlying assumptions can be inaccurate, biased, and lack credibility. For example, if a family-run organization decides to limit their board to family-members only because they collectively assume no one else will promote their mission; then they may be missing incredible opportunities. If, instead, they acknowledge their assumptions, gather facts, and carefully review their options, they may find some remarkable allies.

ACTIVITY 2.2 WHAT ARE YOUR 3 TOP ASSUMPTIONS ABOUT VIOLENCE?

Remember, not good or bad, not value judgments, just your deepest beliefs about violence.

1.

2.

3.

Do they surprise you? Are you aware of them whenever you approach information about the occurrence of some violence? Do you think these assumptions might impact some decisions you make without your awareness?

USE CRITICAL THINKING

Being a critical thinker doesn't mean that you are judgmental or mean. Critical thinking is the ability to carefully and consciously reason your way through your own personal beliefs, assumptions, and prejudices to intentionally consider all available information before drawing conclusions.

Generally, we all make daily decisions – from what to eat for breakfast to which bus to take, to joining a community event or not – based on our own belief systems. From where did our

beliefs come? For example, why do we think a particular cereal is best for our cholesterol? Both personal and group decisions require critical thinking.

THREE STEPS TO IMPROVED GROUP DECISION MAKING

1. Make your own thinking transparent. Share with others in your group why you think what you think.
2. Ask others to explain their reasoning. Ask why they are proposing or opposing a certain decision.
3. Then, focus on the places of real disagreement. Is more data needed?

USE EVALUATIVE THINKING

Another important approach to supporting good thinking and clear decision making is the process of evaluative thinking. That means building upon our personal experiences or observations with the same logic an evaluator uses. Let's take an example.

- I make an observation. *I am driving on a country road and the car in front of me is going very slow.*
- I check and acknowledge my own personal assumptions. *I assume someone driving so slow on a country road just out to see the scenery.*
- I acknowledge the conclusions I draw based on my assumption. *This sightseer doesn't care that I am behind him and in a hurry. He is being disrespectful.*
- I gather more information. *I see a sign saying "Emergency Animal Hospital – next right turn." I see the right turn signal begin to blink on the car in front of me."*
- I realize what I don't know. *The car in front of me may be transporting a seriously injured animal to the emergency hospital.*

The process of evaluative thinking is being aware of what your ideas are based upon, the limitations of what you know, and identifying new information and new sources of information needed to get to a better understanding.

Evaluator, Michael Quinn Patton describes evaluative thinking as “*thinking in terms of what is clear, specific, concrete, and observable*” rather than “*thinking in terms of vagueness, generalities, and untested beliefs*”(p 153). In the same textbook, *Utilization-Focused Evaluation* (Sage Press: 2008), he outlines elements of evaluative thinking.

Evaluative Thinking is critical to family leaders. In order to effectively solve problems, make decisions, or decide in a reasonable and reflective way what to believe or what to do, you must be using *Evaluative Thinking* to truly achieve success. This way of thinking is crucial to improving the quality of life for families and moving forward in the family movement. Here are some of the ways that *Evaluative Thinking* can help family leaders:

- Raise vital questions and challenges
- Frame questions and challenge assumptions clearly and precisely
- Assess relevant information
- Arrive at well-reasoned conclusions and solutions
- Think on a broader and more open-minded level

CHAPTER THREE: GARNERING STRENGTH: FAMILY NETWORKS?

Before going further with how to use data in decision making, this chapter will focus on strengthening the ability of family leaders to be family-driven.

- *Family-to-Family Network Analysis*
- Re-examining the Network Analysis with a Cultural and Linguistic Lens
- Direct and Indirect Communication
- Decision Making Authority

INTRODUCTION TO ASSESSING YOUR NETWORK

The following 5 pages are the steps in this analysis exercise.

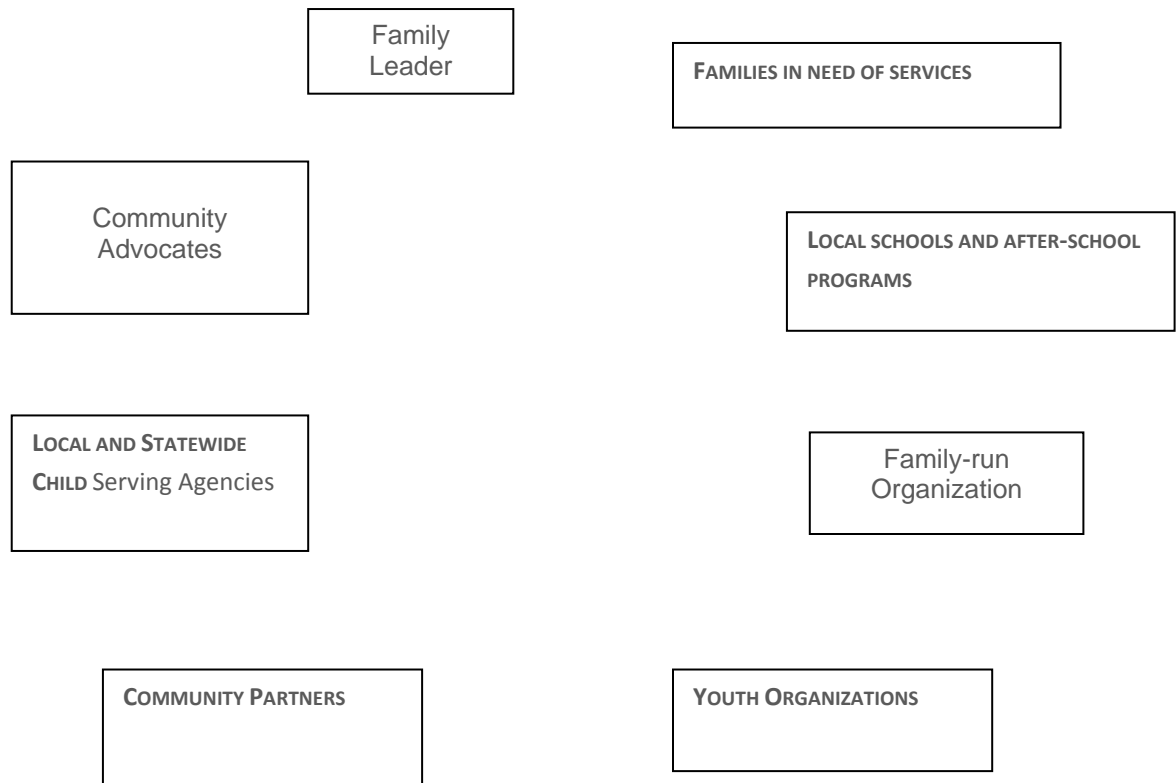
You will need a large piece of paper, butcher paper or a page from a flip chart. You will need red, blue, and green pencils or markers. It might take you 30 minutes to complete by yourself, or longer with other family leaders who have additional information. We recommend that you keep the completed exercise as a reference point as you gather new partners or make improvements to the network you identify.

FAMILY-TO-FAMILY NETWORK ANALYSIS

This is a quick exercise to assess linkages between families and youth in various roles in your community. Weak or missing links can be identified and strategies can then be built to make strong connections and improve the flow of information. Many of the examples use titles, roles, and other entities from federally funded system of care communities. You can replace them with ones that fit your community.

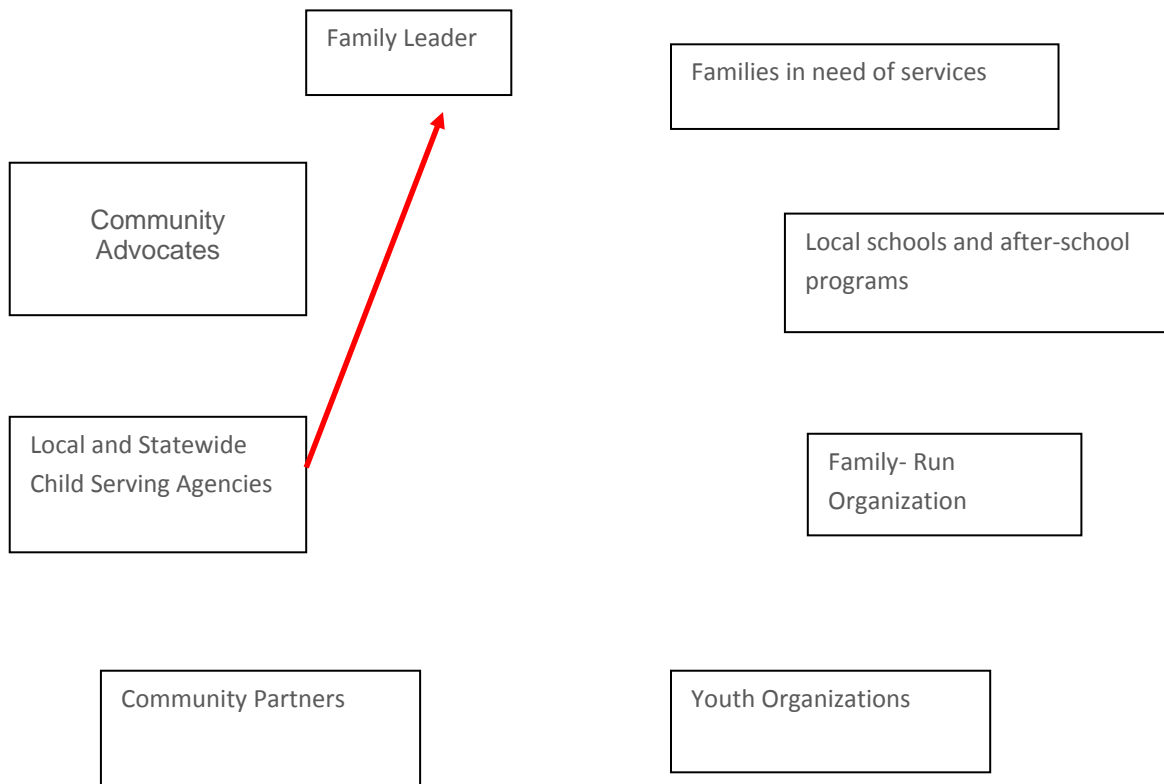
STEP 1

List all the groups of families that might be in your community, all the groups of youth, and all the related agencies, and other partners. On a large sheet of paper, draw a circle or box with a label for each. This exercise begins with families, for simplicity's sake. You can add youth categories and missing family categories as needed to better represent your community.



STEP 2

Using **red** pen or pencil, draw arrows indicating the direct flow of information between families. For example, does the family-run organization share information and resources with the Family Leader?



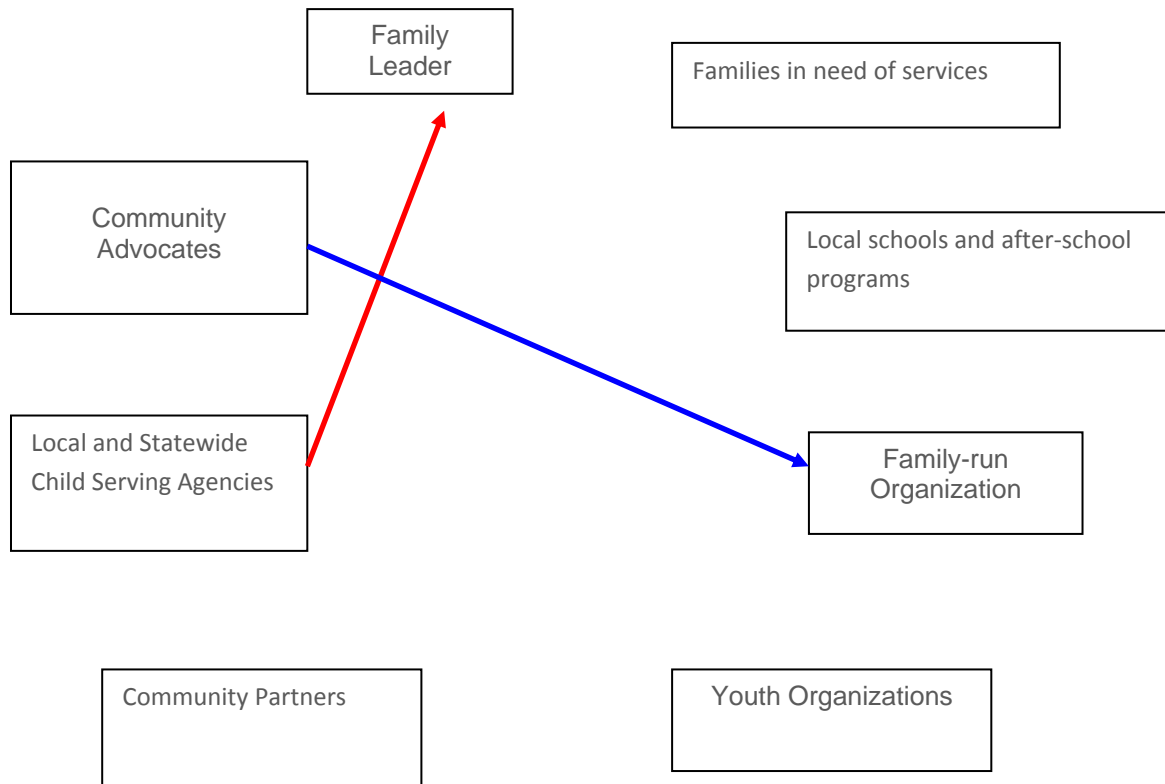
When you have completed this step, stop and study

Where are the communications direct? What strategies support the direct flow of information?

Where are there no direct communications? What strategies could be used to create them?

STEP 3

Using **blue** pen or pencil, draw arrows indicating the *indirect* flow of information between families. For example, do the community partners make presentations or provide trainings that are accessible to community advocates?

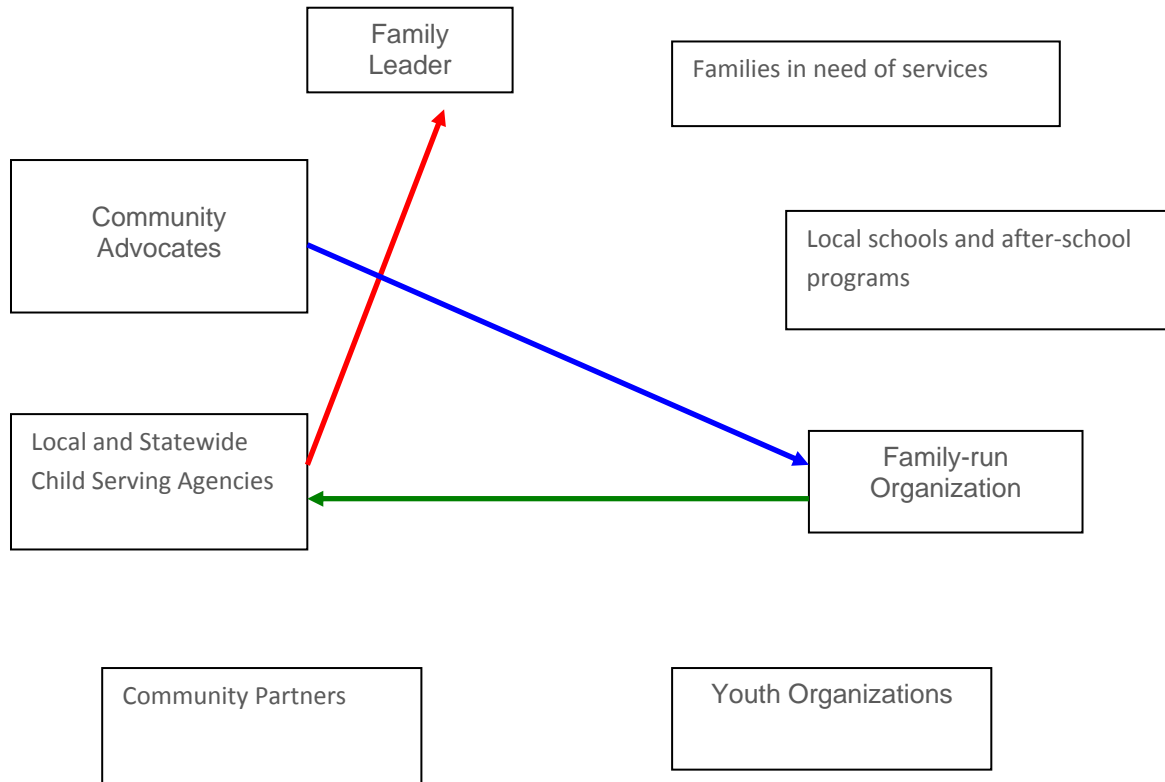


When you have completed this step, stop and study

Where are there indirect communications?
How effective are they for ensuring that all families who need to know are being given access to the information?
Do they need to be more direct communications?

STEP 4

Using **green** pen or pencil, draw arrows indicating the *direction of any decision making authority* that exists between these entities. For example, does the family-run organization have a role in the work being done by the youth organization?



When you have completed this step, stop and study

Related to services, supports and funding, does any family role, group of families, or family organization have power over another? (Considering that decision-making authority can be power.)

Does such authority influence the flow of information about the evaluation in any way?

STEP 5

Where are the strengths in your family-to-family network?

Where are the weaknesses in your family-to-family network?

How can the weaknesses be turned into strengths?

Are there threats that can be turned into opportunities?

CHAPTER FOUR: RESOURCES AND PUBLICALLY AVAILABLE DATA SOURCES

In this chapter we explore data available to the public. Once you have found data sources, how do you determine the source to be “good enough” to use? This chapter will cover the following:

- Critical Questions to Ask of Data
- Finding Publically Available Data
- Creating a Reference List to Ease Future Explorations

CRITICAL QUESTIONS TO ASK OF THE DATA

Prior to conducting a search for relevant research, evaluation or related data, you must first be prepared with criteria for selecting data you will want to use.

While finding data can be time consuming and challenging, the hardest part is yet to come. Just like the researchers who produced the data, you have to do a little research of your own. Asking critical questions of the data will help you determine whether the data meet your need. Practice reviewing data sources with the following questions.

1. What question was this study intended to answer and by who’s definition? (For example, if you are looking for studies of family empowerment, you will want to use studies that define it the same way you do. In other words, you want studies that studied what you are looking for – not just using the same phrases.)
2. Who conducted the study and why were they asking? Can you determine anything about their perspectives, motivations, assumptions, and can you determine who

was funding this? (For example, if you are looking to find good information about the side effects of a particular drug, do you want to rely solely on research conducted by the company that sells the drug?)

3. How was the study conducted? Who was asked? When were they asked? How many people were asked? (For example, if the study on prevailing fashion was conducted in 1968 and men in Australia provided the answers, would this answer your search for data on the fashion of the day in the U.S.?)

If you are unable to answer these questions when reviewing a source, there are people who can help such as a public librarian or a local evaluator.

FINDING PUBLICALLY AVAILABLE DATA

Publicly available data is publically available information that comes from research or evaluation. Data produced from systematic processes that gather a lot of information from many sources and apply scientific methods to understand what it means is more reliable and more valid than simple opinions. Remember our underlying premise for this workbook: if we have good data, we'll make better decisions for the health and well being of our children, youth and families. And, don't confuse data with full databases, datasets, usually called *raw data*.

ACTIVITY 4.1 WHERE DO YOU GET YOUR INFORMATION?

List the top four places you go for information and why you use them.

- 1.
- 2.
- 3.

4.

And, in each of these five places (or sources) who do you go to for help answering the critical questions listed above: perhaps a researcher, a colleague, a librarian? If you don't already have that kind of ally, start brainstorming about whom you might reach out to.

When you find good information, use it responsibly.

- Never use personal or family stories without permission (think informed consent!)
- Use reputable sources of information (avoid hearsay and unsubstantiated claims)
- Always give credit where credit is due. Provide proper citations.

Start with the obvious places:

- Newspapers
- Libraries
- Internet
- Other advocacy groups or government agencies focusing on similar issues

Many newspapers are also available on line. To use a newspaper as a source of information, be sure to go further with your search for information. What are they basing their information on? Is it someone's personal observation? Is it their opinion? Did they interview a researcher? Historical searches of newspaper are great sources of information about previous community initiatives, successes, changes, and so on. They are perhaps not the best source for statistics about children's mental health (unless they are citing a reputable

source like *DataTrends*) or about what works and doesn't work in treating particular disorders.

Libraries are rich places to begin searches and are often complete with friendly research librarians. Go to the desk and ask for help. Tell them what you are looking for and why you need it. Chances are they'll be very helpful and may walk you through the process. In addition to the local public library, ask for access to the libraries in hospitals, research institutions, universities, and military medical facilities. Some will say no and others will welcome you in. You'll find a plethora of resources in specialty libraries like these, which are not available in most public libraries.

If you are in or near Washington, D.C., a visit to the National Library of Congress can be a once in a lifetime kind of experience. It serves as the research arm of Congress and, in addition to beautiful architecture and museum exhibits, millions of books, journals, videos, and so on are accessible there. It is the largest library in the world.

Mentioning the Library of Congress easily brings us to the Internet. You can actually access the Library of Congress at www.loc.gov. You can go further and find information about pending or existing legislation at www.thomas.loc.gov.

The Internet brings with it easy to use search engines, such as Google or Bing. In fact, go to the search engine provided in the tool bar of your internet provider's page. Type in "publicly available data" and be amazed at the list that comes up. In addition, each search engine has its own specialized approaches. For example, you can go to the Google website and download the tools for searching academic literature, Google Scholar.

Specialty websites, such as those that follow, are great resources that you might want to mark as favorites on your internet application.

www.PubMed.gov is sponsored by the National Institutes of Health and the National Library of Medicine and contains 18 million citations.

www.childhealthdata.org is sponsored by the federal Maternal and Child Health Bureau and administered by the National Center for Health Statistics. Prevalence and impact data for a range of children's health issues are available based upon surveys from 2003 and 2007. The surveys included children ages 0-17 in 50 states plus the District of Columbia.

www.cdc.gov/YRBSS includes fact sheets, publications, data files, power point presentations and a do it yourself guide for developing presentation about youth risk behaviors. The Youth Risk Behavior Surveillance Systems (YRBSS) monitors priority risk behaviors among youth and young adults.

www.cdc.gov/NCHS is another Center for Disease Control website area and is for the National Center for Health Statistics. It is a rich source of information about health in the United States.

www.findyouthinfo.org includes demographic data on youth in this country and issues impacting them.

www.cmhi-library.org also known as the Digital Library is a searchable database of National and local evaluation products developed under the Children's Mental Health Initiative of the federal Substance Abuse and Mental Health Services Administration.

So, let’s start a list and create an easy to use reference list for your future explorations.

CREATING A REFERENCE LIST TO EASE FUTURE EXPLORATIONS

ACTIVITY 4.2 CREATE A RESOURCE LIST

Create a worksheet using the following template. Add to it as you discover new resources. Share it with your colleagues and encourage everyone to help keep it up to date. It can make a nice tool for your organization or peer group. You might add other categories into the left column.

WEBSITE RESOURCES	RESOURCE AREA
e.g. www.cmhi-library.org	Children’s mental health related products from SAMHSA systems of care
LOCAL FAMILY-RUN ORGANIZATIONS	INTEREST/RESOURCE AREA
FAMILY LEADERS & ADVOCATES	INTEREST/RESOURCE AREA
OTHER ADVOCACY GROUPS	INTEREST/RESOURCE AREA

CHAPTER FIVE: USING DATA TO MAKE YOUR POINT

In previous chapters of the workbook the focus is on what it means to be family-driven and data-informed; understanding your own sphere of influence; and gaps and potential in your community's family network. We have also explored a number of data sources. Keeping these issues in mind, we shift now to the use of data. As you are moving to influence a particular decision, how do you use data to deliver your message? In this chapter of the workbook we will explore the following:

- Clarifying your message and supporting it with data
- Responding to opposing data or arguments

CLARIFYING YOUR MESSAGE AND SUPPORTING IT WITH DATA

Family leaders and advocates are most often trying to say one of the following things:

- This is the problem and this is who it impacts
- This is the cause (of the problem)
- This is the solution and it works
- This does not work
- This is the cost

Family leaders and advocates are most often trying to say these things to the following:

- Other family members
- Colleagues on influential committees and boards
- Providers
- Administrators
- Researchers

- Legislators
- The public in general

All of this falls under *communication*, which could be an entire workbook all by itself. What are some of the things you have learned from workshops, your own observations, and trial and error about how communication works?

ACTIVITY 5.1 BRAINSTORM IMPORTANT COMMUNICATION TIPS

E.g.: Communication is not complete until it is heard and understood.

E.g.: The higher up someone is, the less time they have to hear your message – adapt accordingly.

With your own list of communication tips, let’s look at how to include the use of data in your message. In years past, family leaders were told that the most powerful way to deliver a message or to influence a decision, especially a policy decision, was by telling personal stories of how children’s mental health disorders and the lack of access to effective treatments had impacted their lives. In today’s world it is increasingly important to include *empirical data*, that is, data that comes from a scientific approach to collecting and analyzing information.

THE MESSAGE: USING DATA TO HIGHLIGHT THE PROBLEM AND ITS IMPACT

Most of us, as family leaders, begin with our own information. Our ideas about what is wrong come from our own personal experiences and those of the other families with whom we network. Finding data to support our ideas and perceptions is a great opportunity for a reality check. Have you ever been upset about a “problem” only to find out that no one else perceived the issue as problematic? (i.e.: the house needs to be cleaned, but no one agrees with you to take action) Or, the reverse, have you ever thought something is a problem only to discover that it is a much bigger problem than you at first thought? Here is where the rubber meets the road for us as advocates. We need to get it as right as we can!

Around 1980, a family member decided the lack of seat belts on school buses was a problem. First, she talked to other parents at the bus stop. Some were equally concerned about it and others were adamantly opposed to it. The second group of parents was not convinced that seatbelts would prevent injury, but were sure they would cost money and result in raised taxes. The local school department’s administrative office responded to an inquiry saying that schools buses were already safe because they were large and bright yellow.

The next stop for this determined family member was the state school department, who stood by the local school administration’s view that school buses were already safe enough. The state department of transportation said they didn’t collect data about school bus accidents because there were so few of them. However, a search at the local library of news reports about school buses in accidents turned up a different story.

If we stop here, we have several audiences and several kinds of data needed to help highlight the problem.

Who?	Needs what information to convince them?
Parents against seat belts on school buses	Data that prove seat belts save lives and perhaps data to underscore the need, like something that shows how many children are seriously injured in school bus accidents
Local school department administrative office	Data that shows that school buses are not already safe
State school department	Data that shows that school buses are in fact involved in serious accidents that result in children being injured

The priority “problem” had shifted. There still were no seat belts on buses, but the problem that needed to be addressed first was that no one thought it was an issue and no one collected data. So, before tackling the seat belt issue, the problem was to address the lack of data. A deeper search came up with nationwide data about the incidence of school bus accidents involving child fatalities.

ACTIVITY 5.2: SMALL GROUP DISCUSSION

With other advocates in your organization or group, read the above example and discuss the question: What would the outcome of this story have been if the family member had not gone in search of data?

The point of this example is to show that searching for data to support any advocacy position can easily lead to problem clarification. Is the problem what you think it is? Does clarifying the problem change the strategies to be used?

The identified problem will determine where the data might be available. What is your primary advocacy issue today? Where are the data to support that as a significant problem and to tell you who is most impacted?

THE MESSAGE: USING DATA TO SHOW THE CAUSE

Once awareness is raised about a problem, we usually need to point to the cause to advocate for change that will eliminate or mediate that source. Cause and effect data requires the most rigorous research methods.

Think about the debate raging in the Autism advocacy world. Many parents have observed their child's onset as closely following their routine immunizations and assumed a cause and effect. As other parents shared similar stories of onset, the larger advocacy arena took on the debate. Were routine immunizations causing autism?

This would be a good example of when on-line searches of scholarly literature would be important. Other sources would be hospital libraries, medical libraries and the Library of Congress.

THE MESSAGE: USING DATA TO DEMONSTRATE THAT SOMETHING WORKS OR DOES NOT WORK

Imagine it is the time of year that budgets are being developed and you, as a family leader, want to be sure that your favorite program is preserved – or that one you don't support is eliminated. What data do you need? Data demonstrating that a program works generally comes from program evaluation and is called outcome data.

Perhaps the task at hand is to ensure your local family-run organization is funded. How can you prove it works and should be sustained? For example, can you find satisfaction levels of constituents?

YOUR AUDIENCE: CONTEXT AND CULTURE

Earlier in this chapter there was an exercise about communication tips. An example offered in that exercise template is that the higher up in an organization, system or government a person is, the less time they will have to listen to your message. In addition to knowing how much time your audience has to listen to you, it is critical to know what is important to them. Ensure that your message is ***useful and relevant*** to the people you are talking to!

Above all, ensure that the race, ethnicity and culture are considered as you craft your messages. Consider the race, ethnicity and culture involved in each of the following.

1. Your own
2. Those who will be impacted by the decision about to be made
3. Those participating in this decision
4. Those who developed the data you are using

WHICH COMES FIRST: THE MESSAGE OR THE DATA?

Throughout this workbook, the approach has varied from discovering data and deciding who to tell – to knowing your message and searching for data to support it. A warning, as we near the end of this workbook: it doesn't matter which comes first. What matters is that your source is credible and that your understanding of it is thorough.

Find comrades who can help. Include academicians and evaluators in your network. Use them to confirm that you are using data the right way. Never -- ever -- ever -- go out with messages about which you have less than a 100% understanding.

RESPONDING TO OPPOSING DATA OR ARGUMENTS

There are volumes in the library about engaging in debate, negotiating, and so on. For family advocates and leaders, we believe there are five basic steps.

1. Listen, listen and listen.
2. Ask clarifying questions about the information or position others are putting forward.
3. Verify that you understand others' perspectives.
4. Seek the point where you have a common agreement, understanding, or goal and acknowledge it out loud.
5. Choose your battles! You can continue to argue. You can suggest more data is needed. You can agree to disagree. You can compromise. Above all, be strategic with your energy and your influence. Choose your battles and choose them wisely.

We want to know what you think.

Please send feedback on this Workbook to:

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