

1. Grab a box Lunch!
2. Find a seat at a table!
3. If there is more than one person at your table from the same state that you are from, please move to a new table!

GOAL: No more than 1 person from each state at each table!
(we might have to make an exception for Texas!)





Serving on Groups That Make Decisions: A Guide for Families INTRODUCTION

Presented by:

Kristi Wees MsChem
Mountain States Regional
Genetics Network



www.servingongroups.org

What brings you here today?



Health



School



Community



Leadership

Agenda

- Workshop Objectives
- Guidebook Overview
 - Family Engagement & Leadership
- Guidebook Sections
 - **1. Opportunities to Get Involved**
 - **2. Types of Groups**
 - 3. Processes Groups Use
 - 4. Tools Groups Use
 - 5. Tips and Strategies for Groups
 - 6. Understanding Data as Information
 - 7. The Role of Families on Groups
 - 8. Skills for Serving on Groups
- Additional Information & Resources



Objectives: Path/Road



- Familiarize yourself with the Guidebook resource and the contents within it
- Build an understanding about decision-making groups
- Learn about the principles that guide group practices and the processes groups use
- Gain strategies to help you confidently and actively participate in a decision-making group



Beliefs in Leadership

- Leaders are not born ~ they rise out of a person's passion for how they want the world to be.
- Leadership isn't a gift ~ it's accessible to anyone who wants it.
- Leadership isn't a calling ~ it's a matter of listening to a question and trying to come up with an answer.
- A leader is anyone who has a very BIG and COMPELLING story of how it could all turn out.

Barbara Walsh, HP
Family Leadership Project



TRUE LEADERS
DON'T CREATE
FOLLOWERS,
THEY CREATE
MORE LEADERS

Leaders become great, not because of
their power, but because of their
ability to empower others.

~John Maxwell

www.gauraw.com

LEADERSHIP
IS ABOUT MAKING OTHERS
BETTER AS A
RESULT OF YOUR PRESENCE
AND MAKING **SURE**
THAT IMPACT LASTS IN YOUR
ABSENCE.

GREAT LEADERS DON'T
SET OUT TO BE A
LEADER...THEY SET OUT
TO MAKE A DIFFERENCE.
ITS NEVER ABOUT THE
ROLE-ALWAYS ABOUT
THE GOAL.

LisaHoisha.com

"If you want to build a
ship, don't drum up the
men to gather wood,
divide the work, and give
orders. Instead, teach
them to yearn for the vast
and endless sea."

— Antoine de Saint-Exupéry

QUOTE QUOTE

ATTRACT
WHAT YOU
EXPECT.
REFLECT
WHAT YOU
DESIRE.
BECOME
WHAT YOU
RESPECT.
AND
MIRROR
WHAT YOU
ADMIRE.

BRIGHTONTHEMAY.COM

The role of a
GREAT LEADER
is not to give
greatness to
human beings, but
to help them extract
the greatness
they already have
inside them.

— J. Buchan

When we take turns doing the hard
tasks, when we encourage others, we
become stronger through shared
leadership.

VERYBESTQUOTES.COM

LEADERS WITH INFLUENCE

GIVE WHEN THEY DON'T HAVE TO.
CARE FOR OTHERS.
GROW CONTINUOUSLY.
LIVE AUTHENTICALLY.
EMPOWER OTHERS.
MANAGE HARDSHIP.
SERVE WITH HUMILITY.

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It does not require
many words to
speak
the
truth.

Chief Joseph
Nez Perce

everybody can be
GREAT
because
everybody can
SERVE

— J. Buchan

Family Engagement & Leadership

- To support and increase participation of families on decision-making groups
- Research on family involvement in the decision-making process have found:
 - Children have better outcomes when families are involved
 - There needs to be support for families



Research of Dr. Joyce Epstein & others



What is Shared Decision Making

HealthIT.Gov

- What is shared decision making?
 - Shared decision making is a key component of patient-centered health care. It is a process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.



Dec 2013

https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf



What is Shared Decision Making

CSHCN definition

- What is shared decision making?
 - Families are considered to have a meaningful role in decision making when the partnership involves all elements of shared decision-making which are: collaboration, respect, information sharing, encouragement and consideration of preferences and values, and shared responsibility for outcomes.



Related to Healthy People 2020 Family Planning Objectives



Benefits to Shared Decision Making

Results for Families

- Awareness and input on policies
- Feeling of ownership
- Shared experiences and connections with professionals and other families

Results for Professionals

- Awareness of family perspectives
- Increased confidence and ability to partner with families
- Acceptance of family representatives in leadership roles



Adapted from studies from J. Epstein & others



Overview of *Serving on Groups*

- Developed due to an identified need
- Collaborative effort by stakeholders
- Audience
 - Family Members
 - Students
 - Educators
 - Groups
 - Community Members
 - Administrators



Sample Page

Opportunities to Get Involved

How can I get involved?
All families have made decisions about their child's care, health and education, whether they realize it or not! Decision-making is an important way for families to be included and heard in the community.



Making a Difference
Once you feel comfortable with the processes that have helped make a difference for your own child, you may choose to reach out and make a difference for other children and families.

It is important to match issues you care about to the decision-making group with the authority to address the issue. This guidebook will help you focus your efforts and take action.

Did you know?
Researchers have found that better decisions are made about programs and services for children when families are involved.

RELATED RESOURCES
For more information about *research on family involvement*, visit: <http://www.cpsbhs.edu/2009/>
For more information about *fastening parent & professional collaboration*, visit: <http://www.parentcenterhub.org/registration/prepare-parent-professional-communication/>

Families Ask Questions

What levels of decision-making can parents be involved in?

"It depends on the group. The most effective groups have families involved at all levels. Even if families haven't been deeply involved before, don't shy away from seeking involvement."
-Courtney, non-profit administrator

"Overall, our district involves parents at almost all levels. In our recent interview process for a new elementary principal, there was a parent feedback group. We have a Parent Liaison that acts as an advisor on various committees. Parents are represented on our committee looking at our "High School of the Future." Parents are also involved in the development of the District 2025 Strategic Plan."
-Robyn, school district administrator

Heading with a Focus Question & Objective

Informative Reading

Real-Life Examples

Facts to Consider

Additional Resources



Family Engagement & Leadership Resources

Family Voices National Center for Family Professional Partnerships

<http://www.fv-ncfpp.org/>

National Center for Parent Leadership, Advocacy and Community Empowerment

<http://www.parentsatthetable.org/>

National Center for Parent Information and Resources

<http://www.parentcenterhub.org>

National Center for Family and Community Connections with Schools

<http://www.sedl.org/connections/>

Family Leadership Project

<http://familieslead.org/>

The Harvard Family Research Project

<http://www.hfrp.org/>

Project Appleseed: National Campaign for Public School Improvement

<http://www.projectappleseed.org/chklist.html>

SEDL Creating Collaborative Action Teams: Working Together for Student Success

<http://www.sedl.org/pubs/fam18/>





Serving on Groups That Make Decisions: A Guide for Families SECTION 1

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Section 1: Opportunities to Get Involved

Questions

- How can I get involved?
- How can I share in decision making?
- Who can serve on these groups?
- Where do I begin?

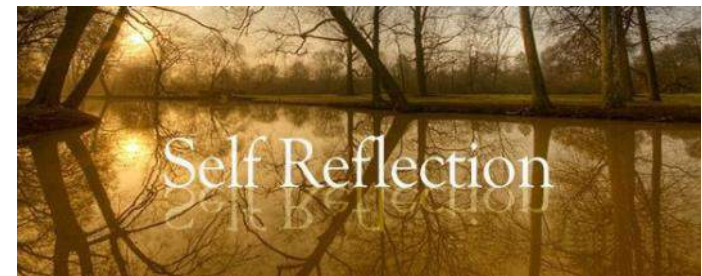
Steps

- Self-Reflection
- Awareness of Possibilities
- Options to Explore

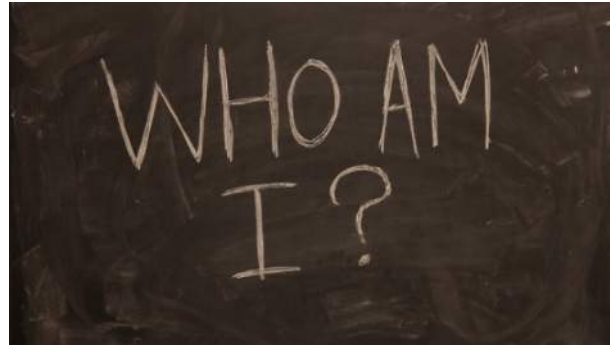


How can I get involved?

- **MAP Activity**



Step 1:



WHO AM I?: How do you describe yourself? Think about:

- What words best describe you?
- What skills, gifts, and talents will support your journey as a member?
- What other skills and talents will you need?
- What do you like/dislike about your current role(s) in working on a team?
- What values and beliefs guide your life and work as a person?
- What relationships with other family leaders and family organizations provide you with needed support?



Step 2: History

HISTORY: Briefly describe the background and circumstances that led you here today.



Think about:

- What is significant about your personal history?
- What is significant about your family, child(ren)'s, or community's history?
- What were your first experiences in which you saw yourself as a leader or part of a decision-making team?
- What adult experiences and/or formal/informal training has helped you see yourself as a member of a group or team?



Step 3: Dreams



DREAMS: What dreams do you have in relation to your personal and professional development as a group or team member?

Think about:

- What contributions and/or changes do you dream about that will involve your participation on a decision-making team?
- What one thing do you most want to see happen?
- What do you hope to accomplish in one year? 5 years? 10 years?
- What other dreams are important to you as you begin this journey?



Step 4: Fears & Concerns

FEARS & CONCERNS: Identify your worries or concerns about becoming part of a decision-making group or team.

Think about:

- What concerns arise when you envision yourself as a leader or member of a team and about your role on the team?
- What barrier might stand in the way of your realizing your leadership and participation dreams?



Step 5: Needs

NEEDS: What needs to happen to make your dreams about leadership and group membership become a reality?

Think about:

- What skills would you like to develop further?
- What else will you need to expand your role as a leader and team member?
- What supports do you need from others? Are you connected to family networks that can provide ongoing support?



Discussion

What common experiences have group members had in relation to each of the MAPS steps?

How will you use the information from your MAP to expand your leadership skills, knowledge and roles?



Shared Decision Making



“Decision-making means a process of partnering, of shared views and actions toward shared goals...not just a power struggle between conflicting ideas.”

-Dr. Joyce Epstein

Who can serve on groups?



Interested Individuals

- Especially if the group's decisions will affect them personally
- BUT choose your opportunity wisely-
focus on your passion!
- AND consider the
TIME & ENERGY
needed to serve

Where to begin?

- Learn about available resources and services
- Find an issue you care deeply about
- Connect to a group with the authority to create or influence change
- Prepare yourself to serve



Section 1 Resources

Family Voices National Center for Family Professional Partnerships

<http://www.fv-ncfpp.org/>

National Center for Parent Leadership, Advocacy and Community Empowerment

<http://www.parentsatthetable.org/>

Fostering Parent & Professional Collaboration – Center for Parent Information & Resources

<http://www.parentcenterhub.org/repository/improve-parent-professional-communication/>

Accessing Parent Groups – Center for Parent Information & Resources

<http://www.parentcenterhub.org/repository/parentgroups/>

National PTA Standards for Family-School Partnerships Implementation Guide

http://www.pta.org/national_standards.asp





Serving on Groups That Make Decisions: A Guide for Families SECTION 2

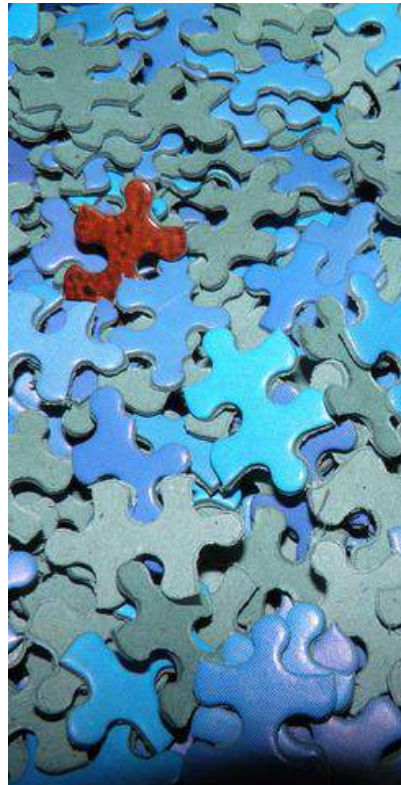
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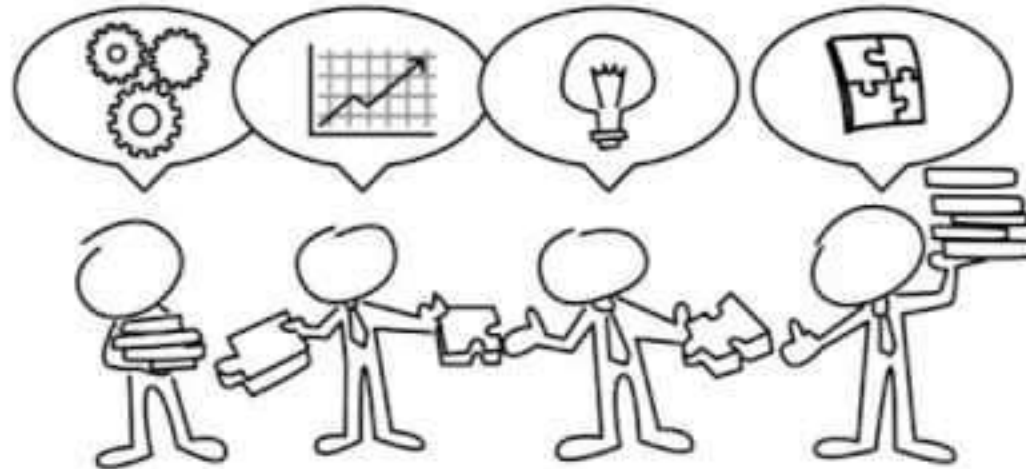
What Makes Decision-Making Groups *Unique*?



- Decision-making authority
- Issues
- Meeting structure
 - Formal? Informal?
- Data used
- Input and feedback
- Processes
- Membership
- History
- Time since formation
- Diversity of perspectives



Member Roles



<https://youtu.be/LmWiBnGkWww>



Sample Page


Definition

Activities

Examples

12

Types of Groups



What is an evaluation group?
Although all groups should spend time evaluating their work together, some groups exist primarily to evaluate the work of others. These groups usually measure the work of large organizations, publicly funded agencies, or large projects.

Activities of an Evaluation Group:

- Create an action plan to explain the steps the group will use to collect, analyze, and report their evaluation results.
- Collect data to measure something and may come from many sources including numbers, surveys, samples and interviews.
- Display data like graphics, pictures and stories to help the data make sense.
- Analyze data, sometimes called *'statistical analysis'*, by asking questions about data and looking for patterns.
- Report results by writing a report to explain what was learned, its conclusions and its recommendations for change.
- *Focus monitoring*, sometimes called *'continuous improvement'*, to pay attention to the quality of services for families and children.

Examples: formal stakeholder groups, service improvement teams, focused monitoring

Remember...
Data can be useful when groups want to measure activities or show results.

Leadership Roles: usually led by a paid staff person or professional

Other Roles: interviewer, assessor, evaluator, family member, consumer or community representative

Length of Service: voluntary or paid staff, could be permanent, or only until their work is complete

Putting It Into Action

The school district implemented a new high school class schedule one year ago. The school board appointed a group of people to evaluate the implementation of the new schedule. The group was made up of administrators, school staff, parents, and students. Some of the activities the High School Schedule Review Group did were to survey teachers, parents, and students, conduct focus groups, and review data on overall student achievement. They analyzed the results, compiled a report, and presented their findings to the school board for their information and to consider if there's a reason to change or modify the schedule.

Leadership Roles

Other Roles

Length of Service

Putting It Into Action

Functions of Groups

Governing

Advisory

Leadership

Planning

Evaluation

Practice



Governing

Activities

- Establish by-laws
- Govern an organization
- Develop policies
- Establish goals
- Communicate with the public & funding sources
- Employ & evaluate executives
- Negotiate with employee groups
- Allow for community participation



Examples

- State or Local School Board
- City Council/Town Council
- Taskforce on Child Abuse and Neglect
- Tribal Council



Advisory

Activities

- Represent a broader group of people
 - Seek out the views of those affected
- Advise on needs
- Bring awareness to issues
- Help develop action plans
- Make recommendations
- Serve as a resource



Examples

- Committee/workgroup
- Advisory Panel
- HMO Advisory
- Title V Advisory Group
- Medicaid Advisory Group



Leadership



Activities

- Initiate awareness of an emerging or systemic issue
- Collectively work on targeted issues
- Conduct listening sessions and public forums
- Actively plan and implement strategies
- Attract a collective voice
- Monitoring entities (watchdog)

Examples

- Associations/Organizations/Coalitions
- School improvement teams
- Community of Care Consortium for CYSHCN
- Initiatives/grants



Planning

Activities

- Research and study a specific issue
- Assess needs and develop priorities
- Make recommendations
- Design information and conduct training
- Develop or select a curriculum
- A channel for communication and feedback
- Plan and carry out an activity

Examples

- Committee
- Workgroup
- Action team
- IFSP/IEP team
- Shared Plan of Care team



Evaluation

Activities

- Create an action plan
- Collect, display, and analyze data
- Report results
- Continuous monitoring for progress and improvement



Examples

- Formal stakeholder groups
- Service improvement teams
- Focused monitoring



Practice

Activities

- Provide a structure to communicate, learn, & act
- Continually reach out to others
- Create opportunities for networking & sharing
- Enhance participation and connections
- Discuss emerging or systemic issues
- Promote interagency connections
- Share information and solutions
- Promote the spread of best practices

Examples

- A learning circle
- A community of practice



Section 2 Resources

Shared Work website

www.sharedwork.org

Guidelines for Establishing Family Advisory Boards

ftp://ftp.hrsa.gov/mchb/training/documents/grantee_products/00_guidelinesforestablishing02.pdf

Serving on Boards and Committees

<http://www.nichcy.org/informationresources/documents/nichcy%20pubs/pa11.pdf>

IDEA Partnership – Practice Groups

http://www.ideapartnership.org/index.php?option=com_content&view=article&id=557:change-theory-organization-development-stakeholder-involvement-in-systems-change&catid=37:reports&Itemid=60

