

Strengthening Your Role: as a Parent Representative

Developed by: Virginia Family Network



Who is NAMI



Who are we?

Families, Individuals, Professionals, and Peer Supporters

What do we do?

Promote mental health recovery through support, education, and advocacy across the lifespan.

NAMI Programs

NAMI Connection Recovery Support Groups

NAMI Family Support Groups

NAMI In Our Own Voice

NAMI Peer to Peer

NAMI Family to Family

NAMI Homefront



what is a Leader?

**Someone who guides a group,
team, or organization to
achieve a common goal.**



Family Engagement and Leadership

Supporting and Increasing Participatation of Families Serving on Decision- Making Groups.

Research has Found:

- **Children do better when Families are invalved in the desision meking prossess.**
- **There needs to be support from families in the desision- making groups when the outcomes of the dessions will effect families.**



Family Leaders are Change Agents

What is needed for effective change:

- A change worth making - **A Better system for kids/families**
- Leadership committed to the change - **YOUR commitment**
- Resources sufficient to make the change - **Partners**
- A plan to use those resources well - **Decision making groups**
- Skills and perseverance to carry out the plan - **YOU**
- An ability to learn from doing - **Your experience/training**

Shift In Thinking

There has been a shift in thinking
FROM Providers and Professionals telling families
what to do.

TO families being involved in the process and
being asked to use their Voice by joining groups
and committees that can improve future
outcomes.



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 perspective
- Increase confidence
- Ability to partner with families and caregivers
- Acceptance of family representatives in leadership role

Take  Action

Making Action Plans (MAPS)

Who I Am

History

Dreams

Fears and Concerns

Needs



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 or dislike about your current role working on teams
- what value and beliefs guide your life and work as a person



History: Background and circumstances

Think About:

- What's significant about your personal history?
- What's significant about your family or children's history?
- Does your community or culture play a role in your history?
- What were your first experiences in which you saw yourself as a leader or part of a decision-making team?
- What experiences formal or informal training has helped you



Dreams: Personal and Professional Devalopment

Think About:

- What contributions or changes do you dream about that your participation may foster?
- What is one thing you want to see happen?
- What do hope to see happen in 1 year, 5 years?



Fears and Concerns: Identify your worries or concerns

Think About:

- What concerns do you have when you think about being a member of a team?
- What barrier may be keeping you from reaching your dreams?



Needs: What needs to happen to meet your GOALS!

Think About:

- **What skills would you like to develop?**
- **What do you need to straighten your roll as a team member**
- **What Supports do you need?**



Reflection

Remembering your Why

Are you observing any recurring themes among the various steps?

How will you use the information from your MAPS to support your role in a decision making group?



Why Sharing Your Story is so Important

- Demonstrating Resilience
- Providing a Role Model
- Offering Practical Advice
- Creating a Sense of Belonging
- Encouraging Vulnerability
- Highlighting Possibilities
- Fostering Empathy
- Motivating Change



Tell your story...

Shared Decision Making

“A process of partnership, of shared views and actions toward shared goals....

Not just a power struggle between conflicting ideas”

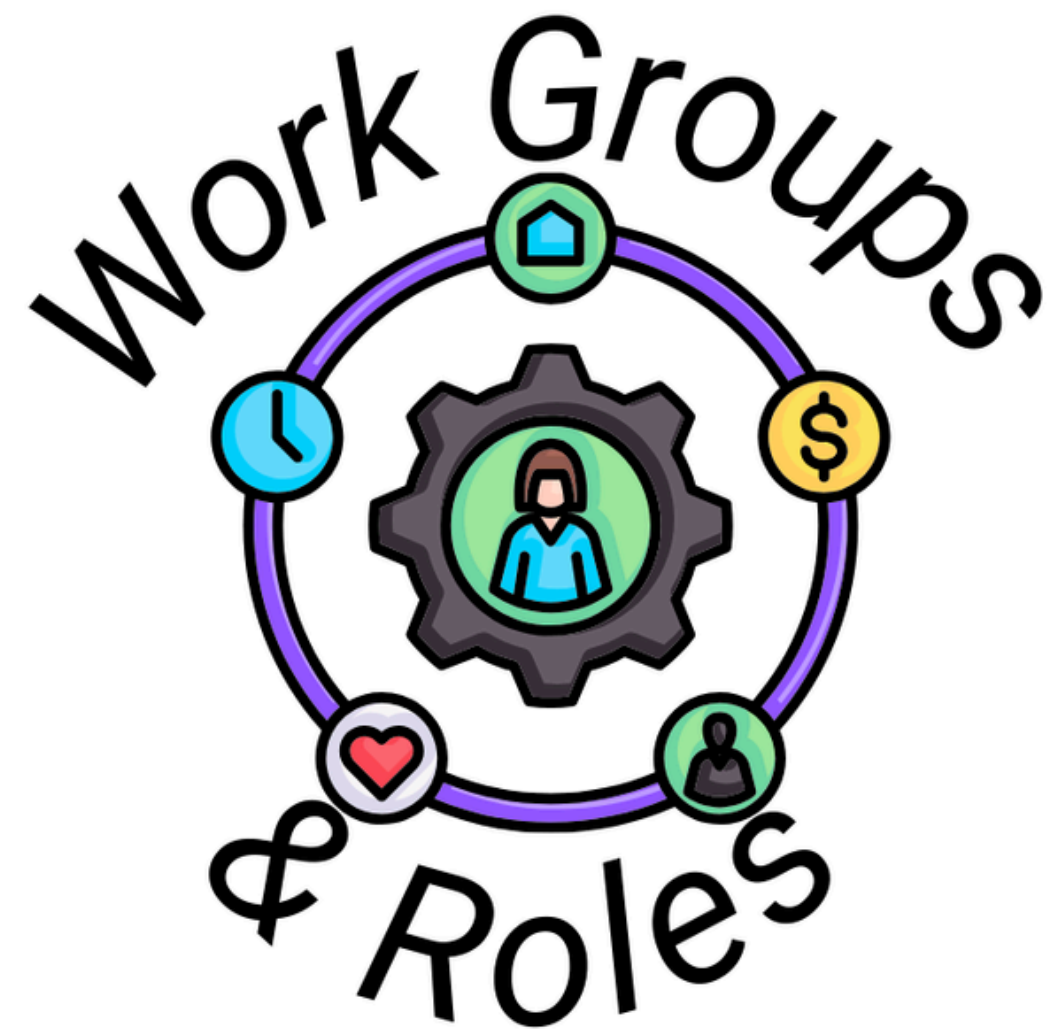
Dr. Joyce Epstein



Considering where to Sit

- The decisions of the group will have an impact on your family.
- The group's focus is a passion of yours
- You have time and energy to invest in to the needs of a work group.





Types of Groups

- **Work Group**
- **Committee**
- **Board members**
- **Advisory Board**
- **FAPT**
- **CPMT**
- **PTA/SEAC**
- **Planning Group**
- **Policy/ Advisory Development team**
- **Program Development team**
- **And more....**



Function of Groups

➤ **Governing**

➤ **Evaluation**

➤ **Planning**

➤ **Leadership**

➤ **Advisory**

➤ **Practice**

Governing

Activities:

- Govern an organization
- Develop Policies
- Establish Goals
- Members usually appointed or elected
- Formal group

Examples:

- City Council
- School Board

Advisory

Activities:

- Represents broader group of people
 - seeks out the views of those affected
- Advise on needs
- Bringing awareness to issues
- Helps develop action plans
- Serve as a resource

Examples:

- Committees/ Workgroups
- Advisory Boards
- HMO Advisory
- Title V Advisory

Leadership

Activities:

- awareness of an emerging or systemic issue
- work on targeted issues
- Conduct listening sessions and public forums
- Actively plan and implement strategies

Examples:

- Associations
- Coalitions
- School improvement teams
- Initiatives

Planning

Activities:

- Reaching issues
- Developing priorities
- Assessing needs
- Making action plans
- Develop curriculum
- Carrying out activities

Examples:

- Case Management
- Workgroups
- Action teams
- IEP/504 teams
- FAPT Teams
- CPMT Teams
- Care teams

Evaluation

Activities:

- **Collect and Analyze Data**
- **Display and Report Results**
- **Monitoring Progress**

Examples:

- **Formal Stakeholder Groups**
- **Improvement teams**
- **Family Engagement Network**

Practice

Activities:

- Provide a structure to communicate, learn, & act
- Continually reach out to others
- Create opportunities for networking & sharing
- Enhance participation and connections

Examples:

- learning circle
- community practice group

Sorting Groups

Governing

City Council

Library Board of
Directors

School Board

Evaluation

NCAA Tournament
Slection Committee
County Audit Committee
Groundwater Quality Evaluation Committee

Parent Teacher Organization

Leadership

Leadership Council for
Human Rights

National Youth Leadership Council

Advisory Council on
Historic
Preservation

Advisory

Task Force for Global
Health

Community of Practice on
Transition

Practice

Child Welfare Policy and Practice Group

Medical Nutrition
Practice Group

School

Palyground
Fundraising
Committee

Planning

Curriculum
Planning
Committee

IEP Team
Local Emergancy Planning Committee

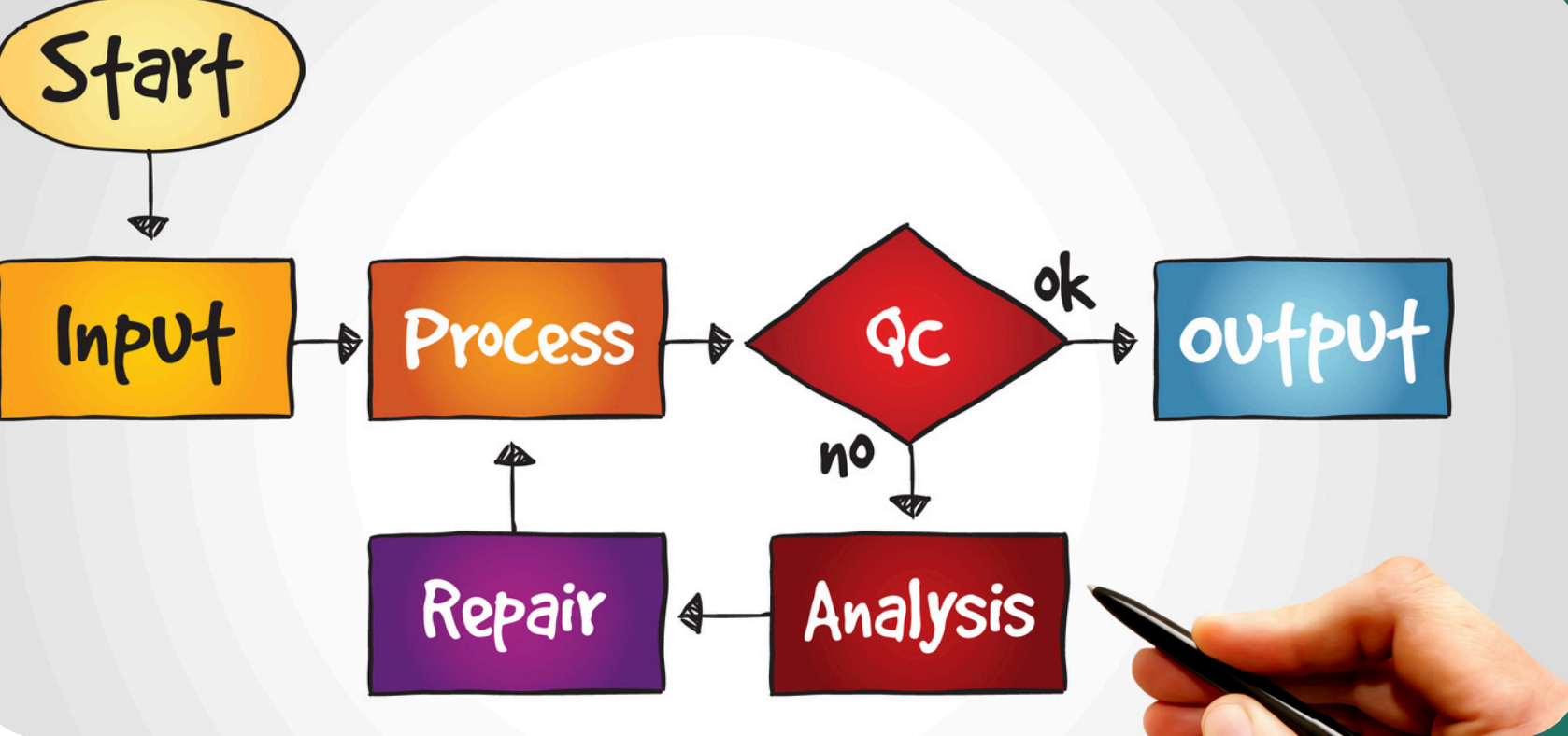
Characteristics of Work Groups



What makes a group unique?

- The issues they are working on
- Goal of the group
- Number of participants
- formal
- informal
- use of sub-committees
- data used
- input or feedback collected





PROCESSES GROUPS USE

▶ Information Gathering

▶ Goal Setting

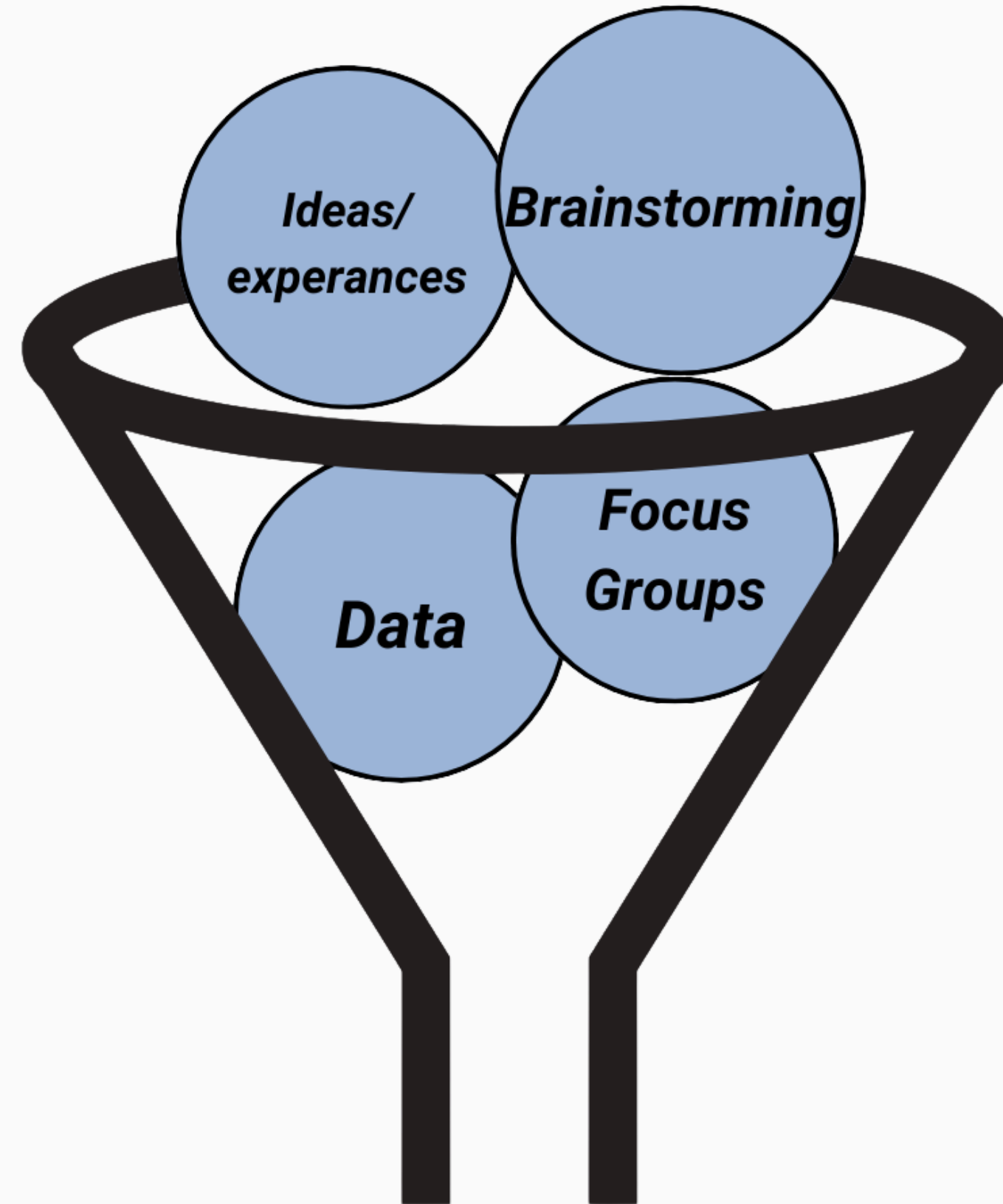
▶ Planning

▶ Collaboration

▶ Evaluation

▶ Reaching Agreements

Information Gathering



Prioritize Issues

Goal Setting



The Vision (what you want.)

The changes the group wants to see happen in the future as a result of their actions.



The Mission (How to get there)

Provides the direction and sets the goals, actions, and decision-making processes of the group.



S.M.A.R.T Goals

Goals written to help the group accomplish what they set out to do and are described as:

- Specific – What are you going to do?
- Measurable – How are you going to do it?
- Attainable – Can you commit to doing it?
- Realistic – Is it doable?
- And Timely – What is your timeframe?

Planning

**The What
The When
and
The How**



Evaluation Testing

Formative



When The **Chef**
Tastes The Noodles

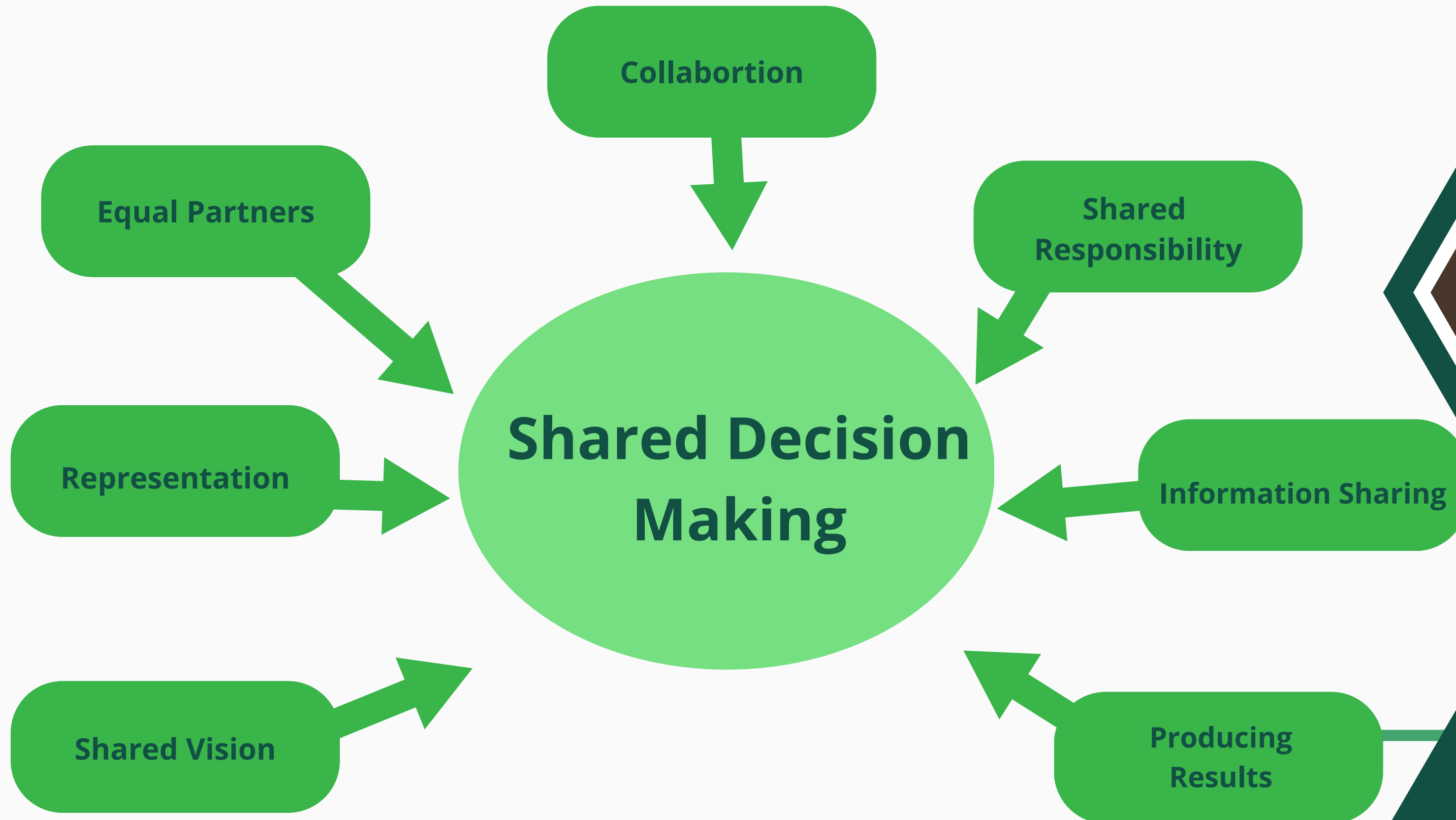
Summative



When The **Guest**
Tastes The Noodles

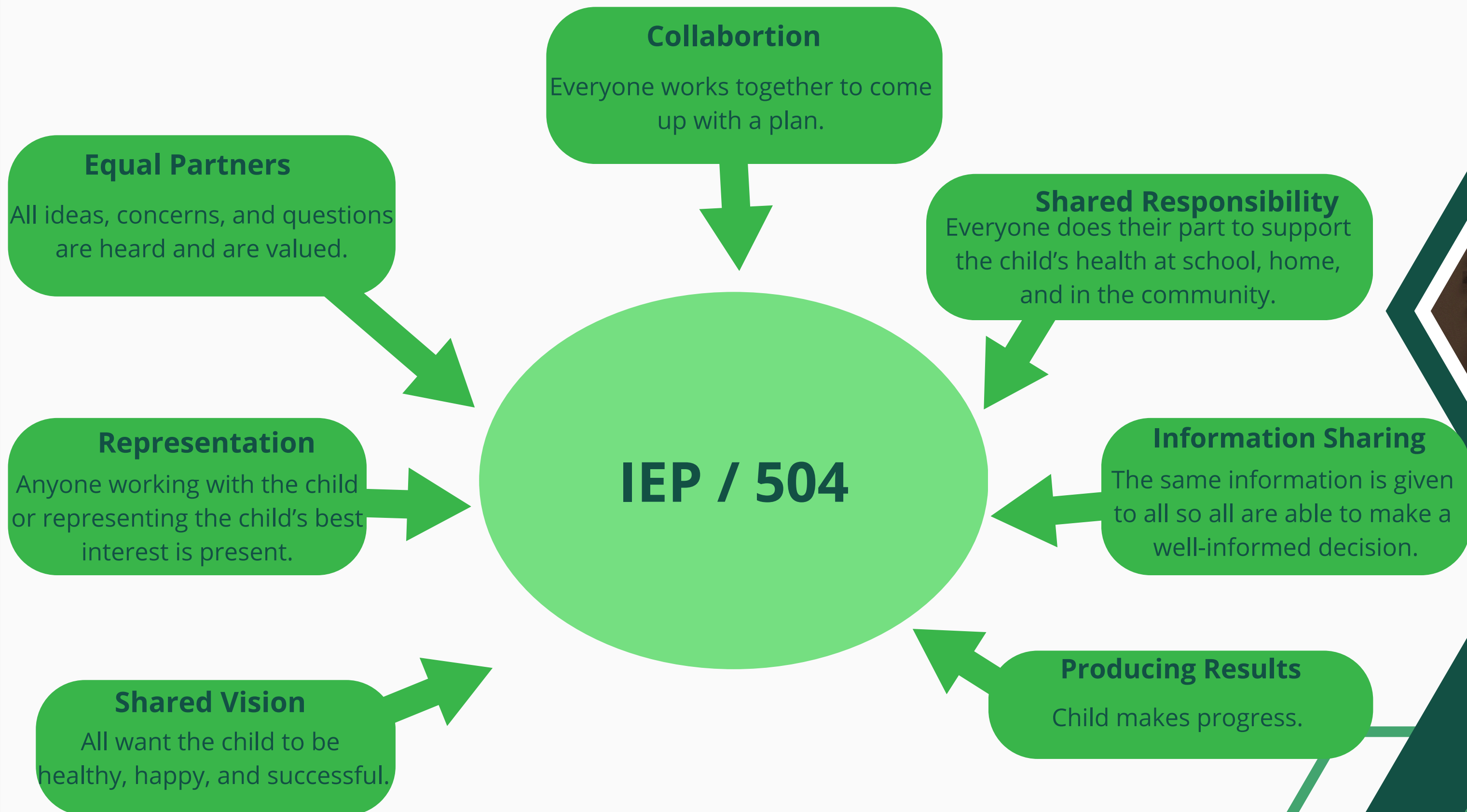
Group Processes

Making a group Decision



Example

Making a group Desision



Helpful Reminders



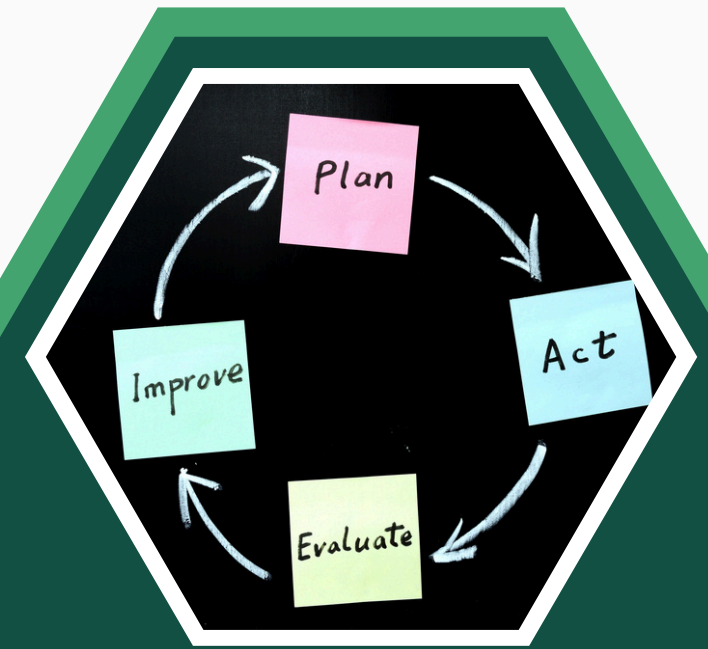
Start With The End In Mind

Focus on the outcomes!
Remember the Target and the Results you're looking for.



Work towards results

Celebrate and Publicize the success



Reevaluate as needed

Be willing to go back and make adjustments as needed

Common Reasons for Unproductive Meeting

- Participants aren't prepared
- No agenda in advance
- Group doesn't follow agenda
- Not everyone considers themselves "participants"
- Data is lacking or decisions made not based on data
- No action items are highlighted
- No timelines or deadlines
- No follow-ups





What is Culture?

► The characteristics of a particular group of people, defined by everything from language, religion, cuisine, social habits, music and arts

www.livescience.com

► The customary beliefs, social forms, and material traits of a racial, religious, or social group

► The characteristic features of everyday existence; a way of life shared by people in a place or time

www.merriam-webster.com

How can a person's culture affect the way they work within a group



Broder Perspectives

Enhanced Problem-Solving



Improved Decision-Making

Enhanced Learning and Growth





*The Significance
of Families Voice*

Choosing a group

Learn about:

- Mission, Purpose, & History
- Style of leadership
- Priorities and goals
- Structure
- Decision-making process

Reminder...

- Review past meeting minutes
- Attend a meeting before joining



Benefits of Family Representation

- Shared Value and Trust
- Loyalty and commitment
- Diverse Perspective
- Conflict Resolution
- Provide A Support System



Your Role in the Group

Family voice in a workgroup plays a crucial role in contributing to the group's overall success.

A team member's role can look like

- Active Participation**
- Task Completion**
- Communication**
- Problem-Solving**
- Flexibility and Adaptability**
- Accountability**
- Support and Encouragement**
- Expertise and Knowledge Sharing**

Challenges Groups Face



Communication

Misunderstandings, lack of clarity, or insufficient communication can lead to confusion and mistakes

Establish clear communication channels
encourage open dialog
use tools to facilitate information sharing

Different Work Styles

Team members may have different working styles which may cause friction

Acknowledge and appreciate diverse work styles, find ways to leverage individual strengths

Cultural Differences

Diverse backgrounds can lead to misunderstandings or cultural clashes

Promote cultural awareness, encourage inclusivity, and attend training on diversity and teamwork if available.

Unclear Goals and Objectives

Unclear or shifting goals can lead to confusion and misalignment within the team.

Set clear, achievable goals, regularly review progress, and communicate any changes promptly

Representing Others



Welcome Input

- Go to where the families are
- Connect with family organizations



Be Accessible

- Attend Meetings in the community
- Provide contact information
- Serve as a liaison between families and the group
- seek out support and support other families



Communicate

- Share a summary of reports of work done during meetings
- Be the link between families and the group

Representing the Group

- **Understanding your Role**
- **Communicate Effectively**
- **Building Relationships**
- **Encouraging Inclusivity**
- **Maintain Confidentiality**
- **Stay informed**
- **Advocate for Trainings**
- **Be Patient and Persistent**
- **Networking**



Overcoming Challenges as a Family Representative

- Multiple Roles
- Communication
- Building Trust and Credibility
- Navigating Conflicts
- Emotional Impact



Make time for Self-care



Prevention of Burnout

Emotional Resilience

Better Decision-Making

Increased Focus and Productivity

Engaging in self-care practices is key to avoiding burnout, a frequent challenge for those in leadership positions.

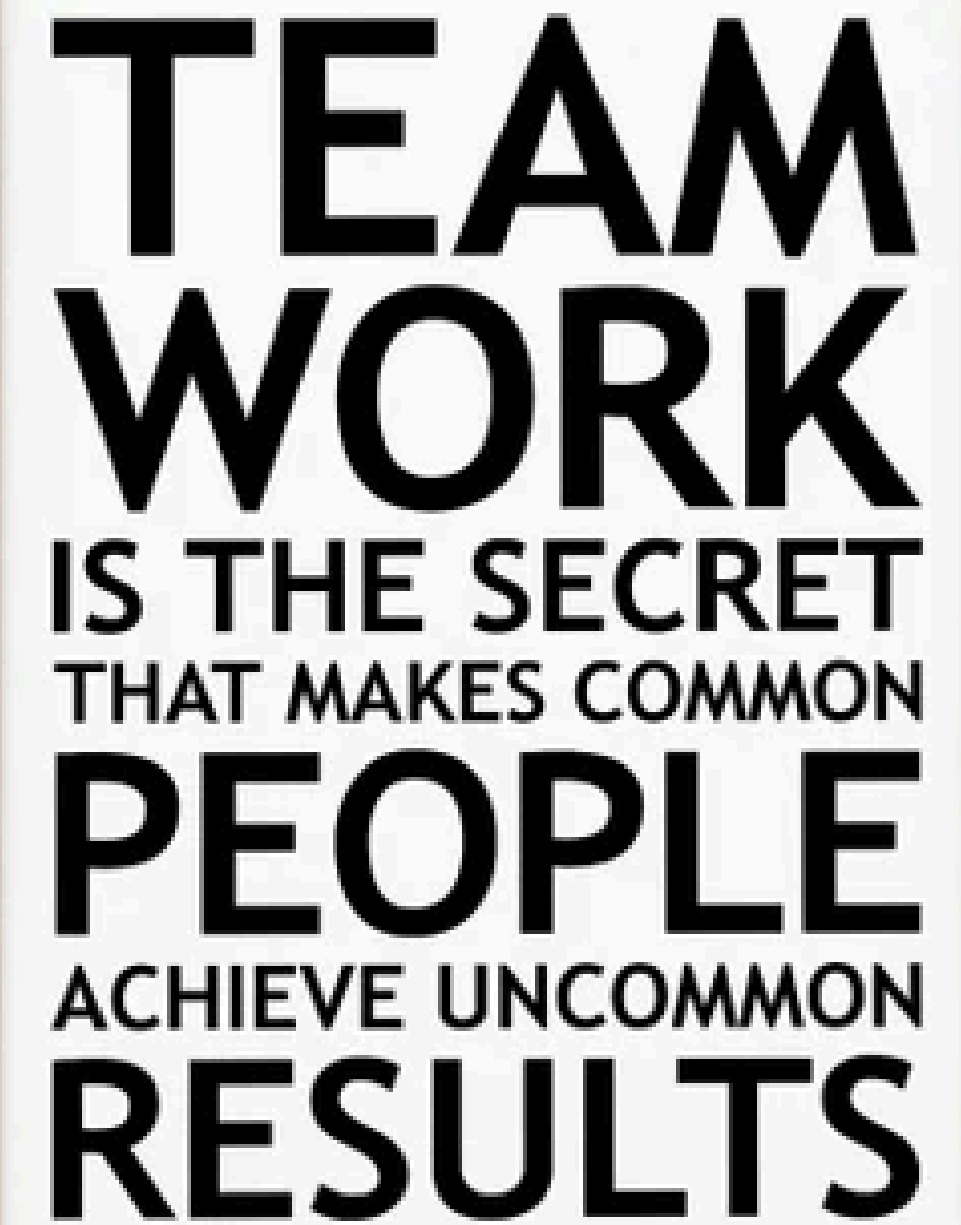
Regular self-care activities, such as mindfulness, exercise, or pursuing hobbies, can boost emotional resilience.

Taking time for oneself often leads to clearer thinking and broader perspectives

Regular breaks and self-care activities can enhance focus and productivity

In Conclusion

- Remember your why
- Your time is important
- Your experience and insight is helpful
- Your voice stands for many



**TEAM
WORK
IS THE SECRET
THAT MAKES COMMON
PEOPLE
ACHIEVE UNCOMMON
RESULTS**

THANK YOU

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