



# The Basics of Effective Advocacy



Jeanine Pinner  
Training & Outreach Coordinator  
Texas Parent to Parent




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## Advocacy

to change "what is"

Into

"what should be"




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## Advocacy



- Gives you a voice in making decisions
- Gives you the power to change relationships
- Helps improve people's lives

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**5 Reasons Why YOU are the Best Advocate for Your Child**

- You know your child best
- You have the unique ability to understand your child's needs
- You are responsible for your child's welfare
- You are a role model for your child
- You have the right to make decisions on your child's behalf

Adapted from Advocacy in Special Education, Andrea Sherwin Ripp

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**Top 10 Characteristics of Effective Advocates**

1. Assertiveness
2. Confidence
3. Motivation
4. Hope
5. Energy
6. Persistence
7. Ability to work with others
8. Ability to find information
9. Ability to use information
10. Believe in your capabilities

Adapted from Advocacy in Special Education, Andrea Sherwin Ripp

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**Advocacy Strategy**



Know...

- Where you are
- Where you want to go, and
- How you can get there

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### Then

- State the problem, or
- State the goal

And...

- Define the challenges and barriers



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### Ask for what you want!



- Make your requests specific
- Define & describe your vision of success

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### Be Assertive, Not Aggressive

- Recognize that each individual has rights
- Believe in your own rights and maintain your commitment to preserving them
- Clearly express your own rights or needs
- Focus on solutions instead of problems
- Promote communication and problem-solving

Adapted from Brain Injury Resource Center <http://www.headinjury.com/>

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## Many Types of Advocacy, including:

**System advocacy:** advocating to change an established system, promoting causes

**Legal advocacy:** lawyers advocating for clients

**Legislative advocacy:** advocating to change laws

**Self-advocacy:** advocating for oneself

**Individual advocacy:** advocating for another

Adapted from Brain Injury Resource Center <http://www.headinjury.com/>

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## Forms of Advocacy



- Writing a check
- Researching a topic
- Verbal exchanges (conversations!)
- Phone calls
- Writing letters
- Monitoring policy meetings
- Organizing others
- Testifying before the legislature
- Participating in public rallies



Adapted from *Making a Difference for Systems Change* Family Voices of Colorado

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Building good relationships with those who work with your child or your family is an important way you advocate for your child.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*, Family Voices of New Jersey Statewide Parent Advocacy Network, Inc.

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Because you know your child's and your family's needs better than anyone, you can be the best advocate for your child.

You can also encourage your child to advocate for himself.

One way he can learn advocacy skills is by observing you, but it is also important to provide opportunities for him to speak and advocate for himself to whatever extent he can.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*, Family Voices of New Jersey Statewide Parent Advocacy Network, Inc.

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### **Six Principles of Self-Advocacy**

- You are valued
- Your voice is important
- You can choose what you want
- You can change things in your life
- You know your rights and responsibilities
- You are part of a supportive community

Adapted from *Advocacy in Special Education*, Andrea Sherwin Ripp

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### **Effective Advocacy**



- Is based on an analytical approach to solving problems
- Increases your chances of getting what you want

Adapted from Brain Injury Resource Center <http://www.headinjury.com/>

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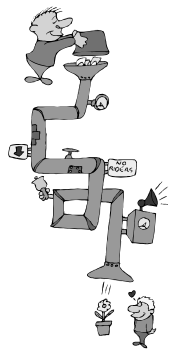
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When you advocate effectively for your own child's needs, you may end up changing a whole system to better meet other children's and families' special needs.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey Statewide Parent Advocacy Network, Inc.

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When you advocate effectively for all children with disabilities and chronic health care needs, you may end up making systems work better for your child and family.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey Statewide Parent Advocacy Network, Inc.

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## To Be a Better Advocate

- Gather information. Ask questions.
- Know your rights.
- Keep organized records.
- Trust that you may see things professionals can't, since you're with your child most of the time.
- Be open to learning new things from those who work with your child.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey Statewide Parent Advocacy Network, Inc.

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## Enlist Allies



One powerful way to advocate for your child is to seek support from other people:

- Other families of children with disabilities and chronic health care needs can share their experiences and what they have found helpful.
- Texas Parent to Parent can help by connecting you with other parents.

Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey      Statewide Parent Advocacy Network, Inc.

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## Find Opportunities to Help Change Systems



Offer to participate in State agency consumer advisory groups working to develop and improve policies and regulations that benefit people with disabilities and chronic health care needs.

Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey      Statewide Parent Advocacy Network, Inc.

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## Find Opportunities to Help Change Systems

Write or phone your local, state or national officials and ask them to support laws and regulations that safeguard Medicaid for children with disabilities and chronic health care needs and their families.



Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey      Statewide Parent Advocacy Network, Inc.

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**Thank your**

- » Providers
- » School Staff
- » Legislators

**when you like what they do.**

Too often they only hear complaints  
from  
clients/consumers/constituents

Adapted from Fact Sheet 3: *Provider Relations and Advocacy*,  
Family Voices of New Jersey    Statewide Parent Advocacy Network, Inc.

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**Nine Questions**



- Can assist you in planning your overall strategy
- Can help guide your specific efforts

Go to: "Nine Questions" - A Strategy Planning Tool for Advocacy Campaigns  
<http://www.advocacy.org/communicate/>

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**Nine Questions**



1. What do you want? (goal)
2. Who can give it to you? (authority)
3. What do they need to hear? (message)

Adapted from: "Nine Questions" - A Strategy Planning Tool for Advocacy Campaigns  
<http://www.advocacy.org/communicate/>

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**A good message is**

- Simple
- To the point
- Easy to remember
- Repeated frequently

Adapted from: "Nine Questions" - A Strategy Planning Tool for Advocacy Campaigns <http://www.advocacy.org/communicate/>

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- People need to hear a message again and again to retain it.
- Simple repetition also builds comfort and familiarity with ideas and issues over time, making the repetition of a well-formed message an important tool in persuading a target audience.
- Using the same message repeatedly promotes retention more effectively than using multiple messages.

Adapted from: "Nine Questions" - A Strategy Planning Tool for Advocacy Campaigns <http://www.advocacy.org/communicate/>

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**Avoid vague words or terms like:**

- |                 |                 |                 |
|-----------------|-----------------|-----------------|
| • Appreciate    | • Confidence in | • Knowledge of  |
| • Attitude      | • Experience    | • Listen to     |
| • Familiar with | • Realize       | • Adjust to     |
| • Feelings for  | • Recognize     | • Responsive to |
| • Capable of    | • Hear          | • Think         |
| • Conscious of  | • Interest in   | • Understand    |

These words are open to interpretation. If you use them, be sure to clarify: explain exactly what you mean.

**Say what you mean and mean what you say!**

Adapted from Brain Injury Resource Center <http://www.headinjury.com/>

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## Nine Questions



1. What do you want? (goal)
2. Who can give it to you? (authority)
3. What do they need to hear? (message)
4. Who do they need to hear it from? (perspective)
5. How can you get them to hear it? (method)
6. What do you have? (resources)
7. What do you need to develop? (resources)
8. How do you begin? (plan)
9. How do you tell if it's working? (evaluation)

Adapted from: "Nine Questions" - A Strategy Planning Tool for Advocacy Campaigns <http://www.advocacy.org/communicate/>

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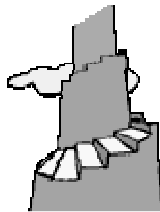
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## 5-Step Advocacy Process

1. Problem definition
2. Information gathering
3. Action planning
4. Assertive action
5. Follow-up



**Don't Get Mad - Get Powerful!** A Manual for Building Advocacy Skills  
<http://www.mpas.org/PubOrders.asp>

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## 1. Problem Definition

- Clear and specific definition of the problem helps minimize waste of time and effort
- Separate facts from feelings
- Distinguish major issues from details
- Getting to the heart of the issue...figure out what's causing the problem
- Defining the problem may lead to ideas for solution

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## Problem Definition, cont'd



- Complex situations may involve several different problems
  - define each
  - may require very different strategies
  - prioritize and work on most important first

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## 2. Information Gathering

- Type of problem determines the type of information needed
- Are there laws or written policies that apply?
- Are there procedures for resolving or appealing disagreements?



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## 3. Action Planning

- Thoroughly analyze the information you've gathered
- Develop
  - one or several alternatives
  - Step-by-step plans
    - Include activities of others who may be helping you
    - Include potential responses to your advocacy efforts
    - How will you deal with the responses to your efforts?
    - Include a schedule. It
      - provides motivation for you to continue working until the problem is solved
      - places some limits on how long you are willing to wait for an active response to your efforts
  - The more detailed your plan is, the better prepared you'll be!



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## 4. Assertive Action



- Carry out the plan you researched and developed
- May involve one or a few steps
  - Writing a letter of complaint, or
  - A whole series of events
- May involve many people or only a few

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## Assertive Action, cont'd

- Requires good communication skills
  - Assertive attitude
  - Active listening
  - Appropriate nonverbal behaviors
  - The use of well-chosen advocacy communication techniques and negotiation strategies



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## 5. Follow-up

- When your advocacy plan results in a verbal agreement to make the change you've been working for...
  - Follow-up to make sure that all agreements reached or promises made are carried out
  - Clarify when changes should be expected and who will be responsible for them
  - Follow-up to see if agreements are actually implemented
  - Write it down! Who, what, when, where...

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Advocacy Notebook  
Discussion Notes

Date: \_\_\_\_\_ Time: \_\_\_\_\_

Kind of Discussion (telephone, meeting, other): \_\_\_\_\_

Discussion with:  
Name: \_\_\_\_\_  
Title: \_\_\_\_\_  
Agency: \_\_\_\_\_  
Address: \_\_\_\_\_  
Telephone: \_\_\_\_\_

Reason for discussion: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Summary of Discussion: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Agreements/Conclusions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Follow-up Needed: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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## A Completed Sample Plan:

### Advocacy Planning Guide

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The problem is:

My 8 year old son, who has a visual impairment and receives special education services, needs speech therapy. This service was not included in his annual individualized education plan and is not being provided.



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**The ideal solution is:**



I believe Ryan needs two half-hour individualized speech therapy sessions from a qualified speech therapist, and one hour of group speech therapy each week to be successful in school and benefit from FAPE (Free Appropriate Public Education).

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**An alternate acceptable solution is:**

I believe Ryan needs two one-hour group speech therapy sessions per week from a qualified speech therapist, and that he needs a speech therapist to show his regular classroom teacher how to work with him to improve his speech.



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**Who has authority to make changes?**

**Name:** John Grant\*  
**Position:** Special Education Director  
**Agency:** Smallville School District  
**Address:** 100 Main  
Smallville, Mi 49100  
**Telephone:** (517) 891-9444

\*As a result of a decision by Ryan's ARD Committee

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**Notes on the chain of command:**

Michigan Dept. of Education, Special Education Service Area



Intermediate School District - Basset County  
Superintendent  
Director of Special Education



Smallville School District  
Superintendent  
Director of Special Education Services  
Principal  
Regular education teacher, special education teachers  
Speech therapist, other professionals

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**Information I Need to Support My Views**

Information I already have:

1. Ryan is eligible for special education services based on the fact that he is legally blind.
2. I have observed that Ryan says words "funny." He doesn't pronounce certain letters, especially: *L, R, S, T* and *TH*. He has done this since he learned to talk.
3. The Michigan Special Education Rules say that speech therapy may be provided as a related service.

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**Information I Need to Support My Views**

Information I already have:

4. These rules also say: (1)related services are those services needed in order for a student to benefit from special education. (2)a student shall be evaluated in all areas of suspected disability, (3)ARD Committees determine services needed and ARD Committee meetings may be convened when necessary.
5. Last month our family doctor said Ryan has not outgrown his speech problems and recommended I look into speech therapy.

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**Information I Need to Support My Views**

Information I already have:

- 6. I had a conversation with Ryan's teacher. She said she has noticed Ryan's speech problem. He is becoming reluctant to talk in class because some of his classmates tease him about his speech.
- 7. According to current research about children's language development, children who don't outgrow speech problems by the age of five or six should receive speech therapy.

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**Information I Need to Support My Views**

Information I still need to obtain:

Ryan needs a speech evaluation to determine what he needs to improve his speech. We must rule out the possibility of a hearing problem - he needs a hearing test. I need to learn and understand the procedures for requesting a new ARD Committee meeting - consult an advocate.

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**My Arguments:**

- Ryan will have to work hard for social acceptance and job success because of his visual impairment. A speech deficit will compound the problem. It is correctable and should be treated.
- He needs the service to participate fully and benefit from his education - his classroom participation in the classroom because of his embarrassment.
- The service is available under special education law.
- Ryan's family doctor has recommended it.

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<p><b><u>Arguments the other party may make:</u></b></p> <ol style="list-style-type: none"> <li>1. Ryan will outgrow his speech problem - therapy is not needed.</li> <li>2. No speech problem has been observed.</li> </ol>	<p><b><u>My counter-arguments:</u></b></p> <ol style="list-style-type: none"> <li>1. Ryan has not outgrown the problem. Children who outgrow the problem have done so by Ryan's age.</li> <li>2. Observations of the problem have been made by me, Ryan's doctor and his teacher.</li> </ol>
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<p><b><u>Arguments the other party may make:</u></b></p> <ol style="list-style-type: none"> <li>3. No staff or money to provide the service.</li> <li>4. They'll make me feel guilty for asking for too much since Ryan already receives teacher consultant services and adaptive aids for his visual impairment.</li> </ol>	<p><b><u>My counter-arguments:</u></b></p> <ol style="list-style-type: none"> <li>3. Lack of staff/money is not a valid excuse for not providing a needed service.</li> <li>4. Services are to be individualized to need student's needs.</li> </ol>
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**My Plan:**

- I'll tape record Ryan's speech. *Tonight*
- Call Ryan's teacher and schedule a teacher conference to discuss the problem. *Call tomorrow 1/14*
- Ask family doctor to write a letter recommending the evaluation. *Call tomorrow 1/14*
- Call advocate to find out how to ask for a new ARD Committee meeting and to review my advocacy plan. *Call tomorrow 1/14*

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### My Plan, cont'd:

- Ask for a new ARD Committee meeting. Write letter? 1/15
- Arrange for someone to attend the ARD Committee meeting with me for moral support. Call Mrs. Jones, Parent Advisory Committee representative. 1/15
- Ask the school to conduct a hearing test and a speech and language evaluation - write letter immediately after teacher conference 1/22
- Attend ARD Committee meeting. Mrs. Jones will take notes so I can listen actively - 2/15?

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### My Plan, cont'd:

- Take new service plan home to review before signing.
- Sign plan if acceptable.
- Follow-up to make sure services are delivered.
  - Talk to Ryan
  - Talk to Ryan's teacher
  - Visit on a scheduled therapy day

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### If My Plan Doesn't Work:



- Call advocate for ideas
- Ask for another ARD committee meeting
- Ask for a hearing

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## Regroup, Revise, Re-think...

- Some steps in the process may need to be repeated
  - If you need additional information
  - Problem may need to be re-defined
- Be flexible
- Try different approaches
- Don't stick with a plan that isn't working
- Keep working until the problem is solved



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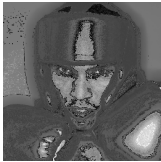
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## Remember: Assertive, ~~Not Aggressive~~



- Recognize that each individual has rights
- Believe in your own rights and maintain your commitment to preserving them
- Clearly express your own rights or needs
- Focus on solutions instead of problems
- Promote communication and problem-solving

Adapted from Brain Injury Resource Center <http://www.headinjury.com/>

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## Good Rules of Thumb...



1. Listen! Ask questions.
2. Make it personal by telling your child's story when appropriate. Keep it brief.
3. Create a relaxed environment by bringing food.
4. Invest in meaningful partnerships with those who work with your child: build, repair, nurture and protect good working relationships.
5. Make sure you understand the position(s) of the people/group you are working with (IEP Team, Legislator, insurance company, etc.).
6. **Follow the Golden Rule:** treat others the way you would like to be or expect to be treated.

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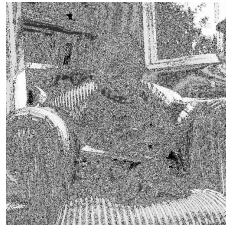
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### Storytelling

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### Telling Your Story:



### *Making a Difference by Making it Personal*

Jeanine Pinner  
Training & Outreach Coordinator  
Texas Parent to Parent



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Parents reveal their stories as a way to explain or understand the past in relation to an imagined future for themselves and their children.



Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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## Stories

- Help us connect
- Reveal the details, the impact of systems on the daily lives of families and children
- Are a powerful way to develop relationships among parents and professionals
- Connect us to our work and to each other in meaningful ways
- Deepen our understanding of individual and shared experiences
- Often spur change in systems that seem impossible to understand
- Can help clarify disagreements

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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## Telling Stories Also

- Helps turn grief and anger into constructive energy
- Influences public opinion by illustrating how policies affect families
- Helps make people feel less alone in efforts to make change
- Shares information that cannot be easily presented by charts or graphs with others who do not directly experience the problem
- Raises awareness and promotes sensitivity

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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Storytelling can also be a huge risk. By sharing a story, you can easily make a point; however, you can also be vulnerable to criticism or misinterpretation.



Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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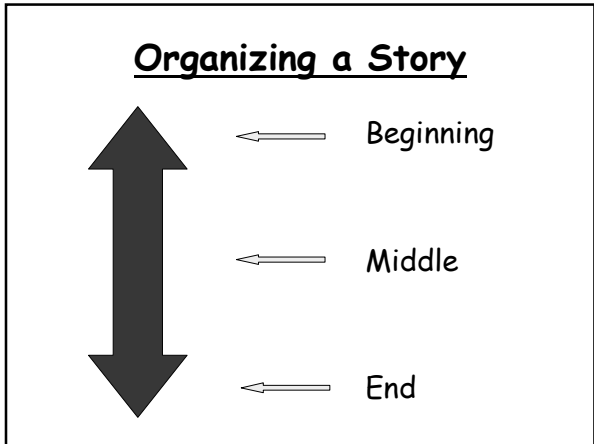
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### Beginning

- Hook
- Sets the stage
- Identifies key characters
- Identifies location
- Gets the listener interested

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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### Middle

- Details
- Adds examples & interesting information

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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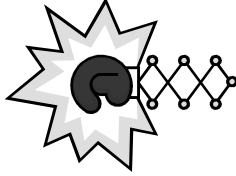
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## End

- Punch line
- Ties things together
- Often gives an idea of what can be learned from the experience
- Theme or lesson
  - Can be stated directly, or
  - Let listeners draw their own conclusions



Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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## Questions to Consider

- Who is your audience?
- What is their purpose?
- What is their education level?
- How many people are in the audience?
- Age?
- Numbers of men and women?
- Numbers of parents and professionals?

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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## A Friend's Story...

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## The Adorable Little Girl & Boy



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### An Important Reminder

As children grow older and more independent, it is important to consult them about the story details and, sometimes, whether or not the story should be told at all. It's important to remember that as children mature, some will be asked to tell their stories and should understand the importance as well as their right to keep details that they deem private to themselves.

Adapted from Glenn Gabbard, Family Experiences: Ways to Lead Change Through Telling Your Story, Early Childhood Bulletin

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# What's **YOUR** Story?

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## Advocacy Resources



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### Resources: Advocacy Skills

- **Advocacy Institute**  
<http://www.advocacy.org/>
- **Brain Injury Resource Center**  
<http://www.headinjury.com/advocacy.htm>
- **Michigan Advocacy & Protection Service, Inc. (publications)**  
<http://www.mpas.org/PubOrders.asp>
- **The Asperger's Connection**  
<http://www.ddleadership.org/aspergers/courses/alifeapart/advocacy.htm>

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### Resources: Self-Advocacy

- **LD Online**
  - (college) [http://www.ldonline.org/ld\\_indepth/postsecondary/nclid\\_selfadv.html](http://www.ldonline.org/ld_indepth/postsecondary/nclid_selfadv.html)
  - (workplace) [http://www.ldonline.org/ld\\_indepth/adult/self\\_advocacy.html](http://www.ldonline.org/ld_indepth/adult/self_advocacy.html)
  - (transition & self advocacy) [http://www.ldonline.org/ld\\_indepth/transition/transition\\_self\\_advocacy.html](http://www.ldonline.org/ld_indepth/transition/transition_self_advocacy.html)
- **Schwab Learning (teens)**  
<http://www.schwablearning.org/articles.asp?r=522>
- <http://www.pai-ca.org/pubs/521501.pdf>
- **Imagine Enterprises** <http://imagineenterprises.com/>
- **Quality Mall (products)**  
<http://www.qualitymall.org/directory/dept1.asp?deptid=1>
- **LD Self Advocacy Manual** <http://www.ldpride.net/selfadvocacy.htm>
- **National Center on Accessibility (recreation)**  
<http://www.ncaonline.org/monographs/14self-advocacy.shtml>

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**Resources: Special Education**

- **It's a New IDEA!** (parent manual)  
<http://www.advocacyinc.org/NewIDEA05.pdf>
- **Wrightslaw** <http://www.wrightslaw.com/>
- **Texas Education Agency - Special Education in Texas**  
<http://www.tea.state.tx.us/special.ed/> (main special education page)  
<http://www.tea.state.tx.us/rules/home/> (Administrative Rules)  
<http://www.tea.state.tx.us/special.ed/explansaf/pdf/eng-ps.pdf> (Procedural Safeguards document)
- **Education Advocacy: A Self-Help Tutorial for Parents**  
Leslie E. Packer (free e-book)  
<http://www.tourettesyndrome.net/Files/AdvocacyTutorial.pdf>

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**Resources: Health Insurance**

- **Advocacy, Inc** (discrimination)  
<http://www.advocacyinc.org/HCS.htm>
- **Texas Department of Insurance** (overview)  
<http://www.tdi.state.tx.us/consumer/health.html>

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**Resources: How to File Complaints**

- **Department of Education Office for Civil Rights**  
<http://www.advocacyinc.org/handouts/ED9-OCRComplaint10-17-05.pdf>
- **Texas Education Agency**  
<http://www.advocacyinc.org/handouts/ED11-TEAComplaint10-17-05.pdf>
- **Texas Department of Insurance**  
<https://wwwapps.tdi.state.tx.us/inter/per/root/consumer/complform/complform.html>
- **Medicaid** Texas Health and Human Services Commission, Office of the Ombudsman, P. O. Box 13247, MC H-700, Austin, Texas 78711-3247, Toll Free: (877) 787-8999, TDD: (888) 425-6889 or (512) 438-3087, FAX: (512) 491-1967  
E-mail: [contact@hhsc.state.tx.us](mailto:contact@hhsc.state.tx.us), [www.hhsc.state.tx.us](http://www.hhsc.state.tx.us)

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**Resources: Community**

• **Advocacy, Inc.**

<http://www.advocacyinc.org/handoutCommServ.htm>

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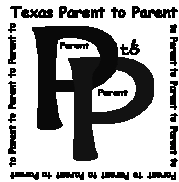
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**THANK YOU!**

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