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## Pediatric Hearing Loss: Providing Effective Parent Support

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**Presented by:**

**Megan D. Ford, AuD**

**Moderated by:**

Carolyn Smaka, Au.D., Editor-in-Chief, AudiologyOnline

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## Pediatric Hearing Loss: Providing Effective Parent Support

Megan D. Ford, AuD



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# UNHS




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## Joint Committee on Infant Hearing

1994 Position Statement

This 1994 Position Statement was developed by the Joint Committee on Infant Hearing, a committee composed of representatives from the American Academy of Pediatrics, the American Speech-Language-Hearing Association (ASHA), the American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNS), the American Academy of Audiology (AAA), and the American Academy of Pediatric Otolaryngology (AAO-Peds). The committee was formed in 1988 to address the need for a coordinated effort to improve the care of children with hearing loss.

### Position Statement\*

The Joint Committee on Infant Hearing affirms the goal of universal detection of children with hearing loss as early as possible. It recognizes that hearing loss is a medical condition that must be identified as early as possible.

### I. Background

In 1988, the Joint Committee on Infant Hearing recommended detection of children with hearing loss as early as possible. This recommendation was based on the knowledge that early identification and intervention are critical to the development of language and cognitive skills.

It is essential that all children with hearing loss be identified as early as possible. This is because the earlier a child is identified, the earlier they can begin to receive the services they need to develop their language and cognitive skills. The Joint Committee on Infant Hearing recommends that all children with hearing loss be identified by the age of 18 months.

### The 1988 Position Statement

The 1988 Position Statement expressed the goal of universal detection of children with hearing loss as early as possible. It recommended that all children with hearing loss be identified by the age of 18 months.

### II. Technical Considerations

The 1988 Position Statement also addressed the technical considerations of universal detection of children with hearing loss. It recommended that all children with hearing loss be identified by the age of 18 months.

A. Identification of children with hearing loss is essential to the development of language and cognitive skills. This is because the earlier a child is identified, the earlier they can begin to receive the services they need to develop their language and cognitive skills.

### B. Identification of children with hearing loss is essential to the development of language and cognitive skills.

This is because the earlier a child is identified, the earlier they can begin to receive the services they need to develop their language and cognitive skills.

### C. Identification of children with hearing loss is essential to the development of language and cognitive skills.

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# Developmental Emergency




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## JCIH 1994 Position Statement

### **Part IV. Early Intervention:**

*“Components of an early intervention program for children with hearing loss and their families should include: **Family support and information** regarding hearing loss ... Professional, consumer, state and community-based organizations should be accessed to provide ongoing information regarding legal rights, educational materials, **support groups** and/or networks, and other relevant resources for children and families.”*



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## JCIH 1990 Position Statement

- Proposed newborn hearing screening for high risk population
- “Family education, counseling and guidance including home visits and **PARENT SUPPORT GROUPS** to provide families with **INFORMATION**, child management skills and **EMOTIONAL SUPPORT** consistent with the needs of the child and family and their culture”



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## PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Evaluation of the Universal Newborn Hearing Screening and Intervention Program  
Shanna Shulman, Melanie Besculides, Anna Saltzman, Henry Ireys, Karl R. White  
and Irene Forsman  
*Pediatrics* 2010;126:S19-S27  
DOI: 10.1542/peds.2010-0554F

The online version of this article, along with updated information and services, is located on the World Wide Web at:  
[http://www.pediatrics.org/cgi/content/full/126/Supplement\\_1/S19](http://www.pediatrics.org/cgi/content/full/126/Supplement_1/S19)



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Evaluation of the Universal Newborn Hearing  
Screening and Intervention Program  
Shulman et al; Pediatrics 2010

- 38 states estimated that only 40% families linked with support programs
- 1/3 of UNHSI providers' had insufficient knowledge about family support



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# Emergency Assistance



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**Problem:**  
Developmental Emergency  
*without*  
Emergency Assistance



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**Effective**



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**Efficient**



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## Smart Family Support

- **Effective**
  - Maximize Benefit
  - Universal
- **Efficient**
  - Minimize cost
  - Just In Time (JIT)
  - Keep It Simple (KIS)



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## Step 1: Identify Parent Needs



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## Who is the parent?



### Identifying Parent Needs:



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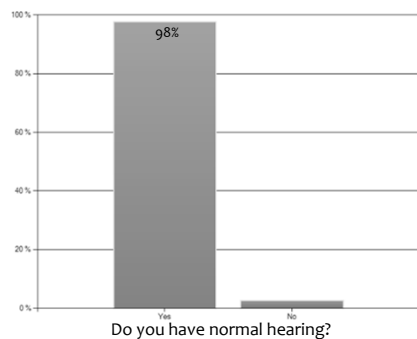
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## The parent has **normal hearing**




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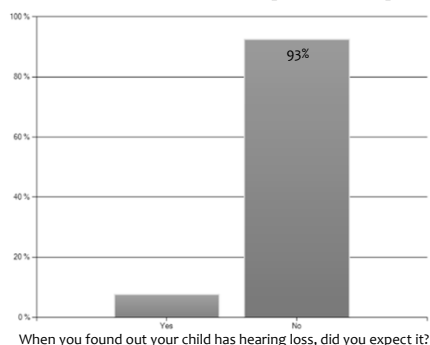
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## The parent **was caught off-guard**




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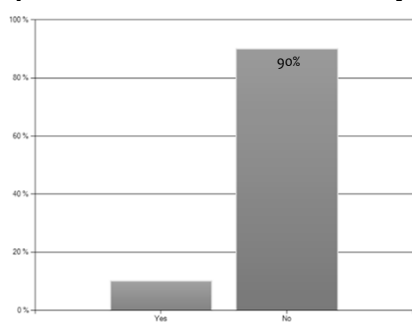
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## The parent **does not have peers**




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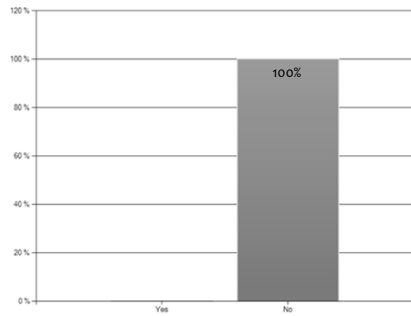
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## The parent has **missing information**



Did you feel fully equipped with the knowledge of how to raise a child with hearing loss?




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## The parent has **strong emotions**

“Crushed”

“Overwhelmed”



“Shocked”

“Confused”

“Devastated”



“What did I do wrong?”

How did you feel when you were first told your child has hearing loss?




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## Summary: Identify Parent Needs

### Who is the parent?

- Normal hearing
- Did not expect this
- Has “unknown” Peers
- Lacks education and information
- Strong emotional reaction to “emergency”




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## Step 2: Address Parent Needs



- Psychosocial needs
- Psychoeducational needs
- Psychoemotional needs




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How do parents want their needs met?



**Addressing Parent Needs:**




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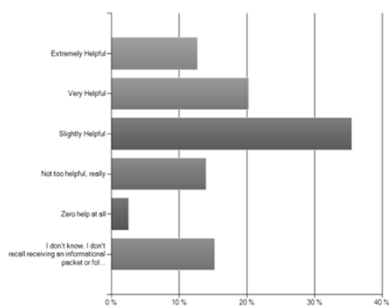
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Written Information is **slightly helpful**



How helpful was written paperwork/informational folder?




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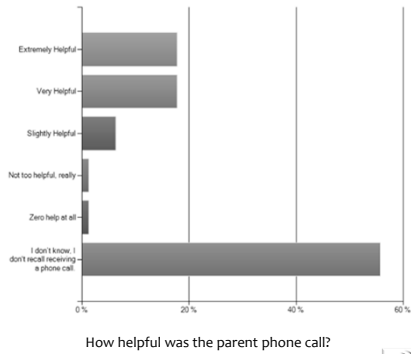
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## Phone calls are **forgotten**



How helpful was the parent phone call?




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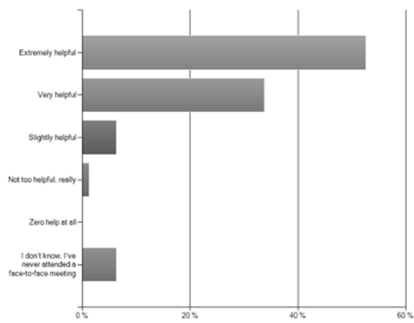
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## Support groups are **extremely helpful**



How helpful are face to face support group meetings?




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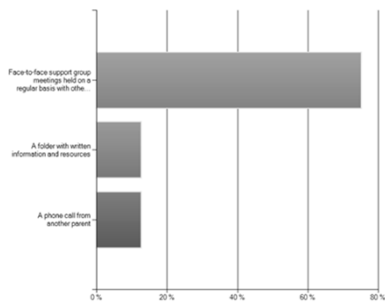
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## Parents choose **support groups**



If you could choose only one form of family support, which would it be?




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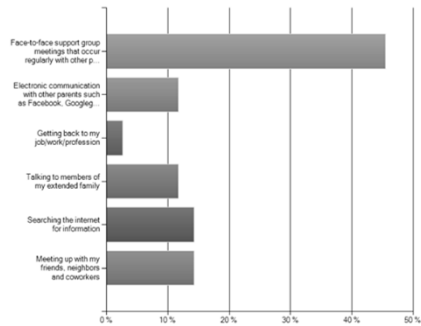
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## Support groups over other supports



Where do you find the most support to address your needs?




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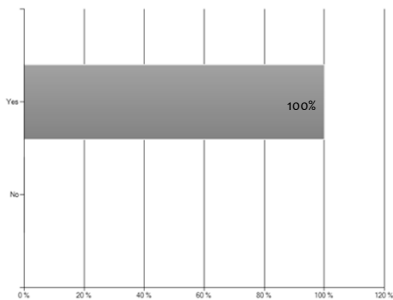
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## Parents **recommend** support groups



Would you recommend a support group to other parents?




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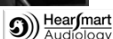
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## Summary: Address Parent Needs How do parents want their needs met?

- Support group meetings
- that gather in person
- on a regular basis




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## Support Group Meetings



- Critical factors
- Regularly scheduled
- Face to face meetings




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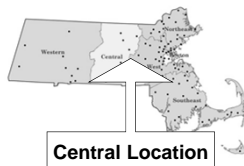
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## Support Group Meetings




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## Support Group Meetings



Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9 Support Group Topic	10	11	12	13

Fixed-Frequency and Re-occurring




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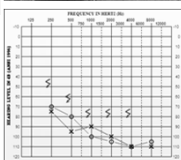
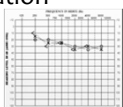
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## Support Group Meetings

### Irrelevant:

- Age of child
- Degree of hearing loss
- Type of hearing loss
- Access to sound type
- Mode of communication



Make it Universal- Welcome All!




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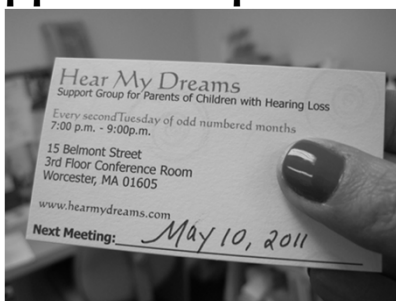
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## Support Group Meetings



Getting parents there




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## Support Group Meetings



Refreshment Sign-ups & RSVPs encourage attendance




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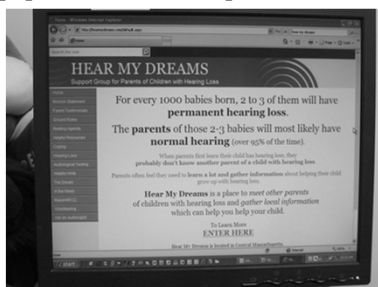
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## Support Group Meetings



Electronic Communication- Website



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## Support Group Meetings

With a parent email list, you can:

- Share local info
- Send reminders of meetings
- Ask for RSVP to meetings
- Enhances attendance
- Encourages commitment



Electronic Communication- Email



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## Support Group Meetings



Electronic Communication- Social Networking



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# Support Group Meetings

## Ground Rules for Support Groups

This is a mutual self-help group, not a therapy group. Hopefully, this group will provide emotional, psychological, and moral support for its members. Each of us is encouraged to participate to whatever extent we feel comfortable. The following ground rules facilitate the development of trust in the group and enable us to share our thoughts and feelings with each other.

1. Because confidentiality is essential, we expect that each person will respect and maintain the confidentiality of the group. What is said in the group is not to be repeated or discussed at any other time or place.
2. We are here to share our own feelings and experiences; we try not to give advice.
3. We each share the responsibility for making this group work.
4. We try to accept people, just as they are, and we avoid making judgments.
5. We try to give everyone an opportunity to share.
6. We have the right to speak and the right to remain silent.
7. We give supportive attention to the person who is speaking and avoid side conversations.
8. We avoid interrupting. If we do break in, we return the conversation to the person who was speaking.
9. We have the right to ask questions and the right to refuse to answer.
10. We try to be aware of our own feelings and talk about what is present to us now, rather than what life was like for us in the past.
11. We do not discuss group members who are not present.
12. We begin and end our meetings on time.

Permission was given to print "Ground Rules for Support Groups" by Certified Counselors of the Association of St. Paul and Minneapolis. For information to purchase the Student Manual for Peer Support Group Facilitator Training, write to: Adams Learning, LLC, 1075 University Ave., St. Paul, MN 55117 or call 651-655-0221 or email [adams@adamslearning.com](mailto:adams@adamslearning.com)

## Ground Rules



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# Addressing Parent Needs

In the support group setting



- Psychosocial needs
- Psychoeducational needs
- Psychoemotional needs



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# The Psychosocial need:



Introductions



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## The Psychosocial need:



Introductions



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## The Psychosocial need:



Nametags



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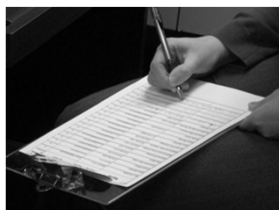
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## The Psychosocial need:

- Establishing parent connections
- Enabling relationships to form outside of the group setting



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## The Psychoeducational need:



Just in Time (JIT) Information



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## The Psychoeducational need:



Guest speakers



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## The Psychoemotional need:

# Outsource?



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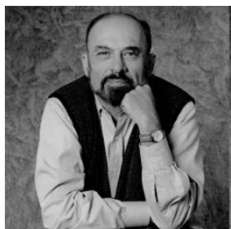
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## The Psychoemotional need:

- Irvin Yalom, M.D.
- Most noted expert of Group Psychotherapy
- Emotional needs met through group meetings



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### Dr. Yalom's 11 Therapeutic Factors

1. Instillation of Hope
2. Universality
3. Imparting Information
4. Altruism
5. Corrective Recapitulation of the primary family experience
6. Development of socializing techniques
7. Imitative Behavior
8. Interpersonal Learning
9. Group Cohesiveness
10. Catharsis
11. Existential Factors



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### Dr. Yalom's Therapeutic Factors

1. **Instillation of Hope**
2. **Universality**
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4. **Altruism**
5. Corrective Recapitulation of the primary family experience
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### Dr. Yalom's Therapeutic Factors

- **Instillation of Hope**
- **Universality**
- **Imparting Information**
- **Altruism**
- **Interpersonal Learning**
- **Group Cohesiveness**
- **Catharsis**

as they apply to a parent support group model



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### The Psychoemotional need:

- **Instillation of Hope**
- **Universality**
- **Imparting Information**
- **Altruism**
- **Interpersonal Learning**
- **Group Cohesiveness**
- **Catharsis**



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### The Psychoemotional need:

- **Instillation of Hope**
- **Universality**
- **Imparting Information**
- **Altruism**
- **Interpersonal Learning**
- **Group Cohesiveness**
- **Catharsis**



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## The Psychoemotional need:

- Instillation of Hope
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## The Psychoemotional need:

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## The Psychoemotional need:

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## The Psychoemotional need:

- Instillation of Hope
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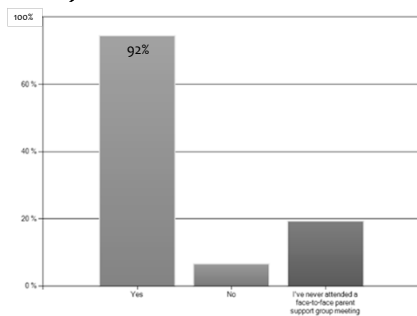
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## Accomplished: Instillation of Hope



Do you feel more hopeful about your child's future since attending a support group?




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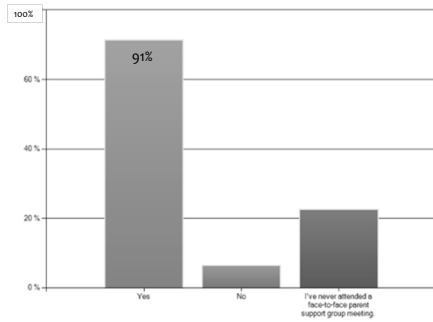
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## Accomplished: Imparting Information



Have you gained information and education that helps by attending a support group?




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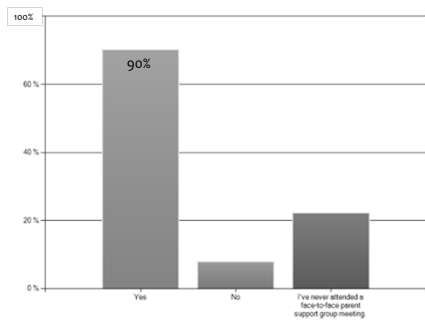
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## Accomplished: Altruism



Do you believe you've helped another parent by attending a support group?




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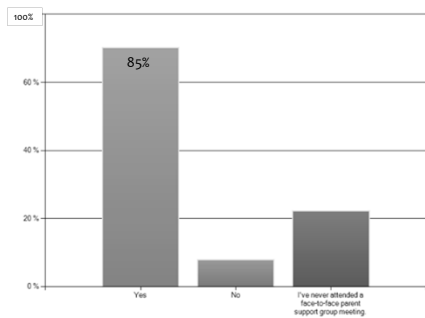
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## Accomplished: Group Cohesiveness



Do you feel more "connected" with other parents since attending a support group?




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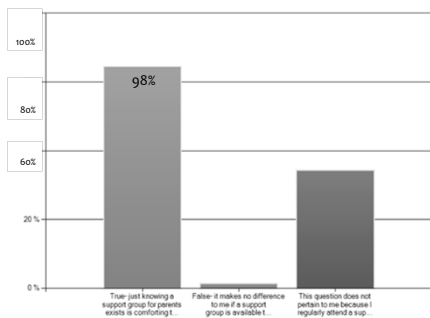
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## Accomplished: Universality



I feel comforted knowing that there is a support group available if I ever needed it.




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## The Group Facilitator

### Parent/Peer driven

- Genuine Empathy
- Cost effective??
- Can become Exclusive
- Risk of Focus shift
- Strong personality domination
- Lack of uniformity
- Lack of neutral moderator
- Children grow up!

### Professionally led

- Objective clarification
- Volunteer??
- Regulates Universality
- Acts as a Filter
- Regulates ground rules
- Exhibits uniformity
- Acts as a neutral moderator
- Stable, open-ended structure




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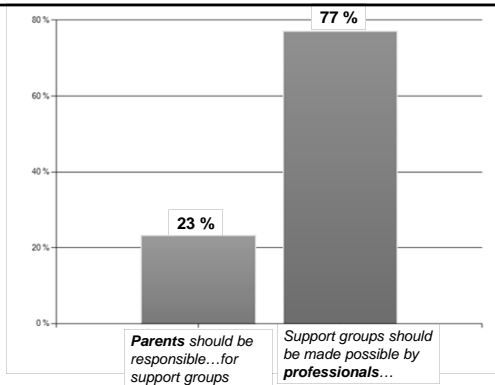
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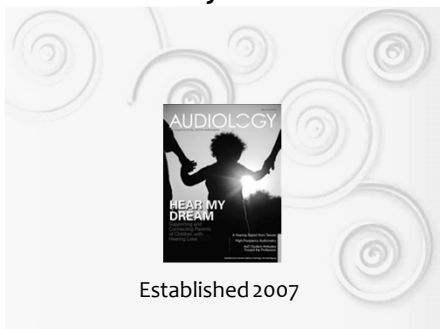
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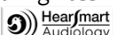
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## Hear My Dreams



Support Group for Parents of Children with Hearing Loss



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## Tying it all together



Annual Meet and Greet



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## Large Catchment Area



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www.hearmydreams.com



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Accountability



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UPSG



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Thank You!

**hearsmartaud@gmail.com**



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