



INDEPENDENTLY MERGING PARENTS ASSOCIATIONS of CALIFORNIA TOGETHER for deaf and hard of hearing children

formation of a Parent Support Group

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WHY A PARENT SUPPORT GROUP?

There are many reasons for a parent support group. The most basic reasons are:

- to help you help your deaf or hard of hearing child;
- to help you help yourself.

A parent support group can give you power to:

1. Get those services your deaf or hard of hearing child is legally entitled to.
2. Become an effective advocate on behalf of your child and other deaf and hard of hearing children.
3. Get legislation passed to provide those services your child needs which are not yet provided by law.
4. Get better services from public and private agencies
5. Open a school, day care center recreational program, workshop, and public school special program, independent living center, or other program your child needs.
6. Make the public aware of the special needs of deaf and hard of hearing children.

A parent support group can also help you:

1. Get the encouragement and comfort you need to help your child.
2. Get acquainted with other parents with similar problems, parents you can work with for mutual help.
3. Plan for your child's future and work to provide him/her with better schools, better work opportunities, better housing, transportation, and recreation facilities.

You may feel the need to organize a parent support group where there is already one in existence - if that group does not meet the needs of your child.

Whatever your child needs, an effective parent support group can help you get it.

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PARENT POWER

A parent support group can help you develop parent power, if it is harnessed and joined with the power of hundreds or thousands of other parents like yourself.

One parent alone can do a lot if he/she is determined enough and willing to work hard enough to get what his/her child needs. But that same parent can do so much more, working with other parents, through an organization that is effective, an organization that is not afraid to use its power to move bureaucracies.

PARENTS KNOW BEST

Parents are the first teachers of their children and know him/her best it's up to them to watchdog their child's services, and make sure that their child gets everything he/she is entitled to by the Individuals with Disabilities Education Act, (IDEA).

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ORGANIZING AN EFFECTIVE PARENT SUPPORT GROUP

ORGANIZING A PARENT SUPPORT GROUP AT YOUR CHILD'S SCHOOL

To organize a parent support group at the public or special school your child attends, follow these steps:

1. Write a letter to all parents (this can be a form letter which you mimeograph or have Xeroxed, or it can be a personal letter), announcing a meeting to form a parent support group. Tell them why you feel a parent support group is needed. List the problems which you would like to discuss with them at the organizing meeting. End the letter by saying you would like suggestions from them on how to resolve these problems, and you would like their help in forming a parent support group to carry them out.

Sample Letter

CALLING ALL PARENTS OF DEAF AND HARD OF HEARING CHILDREN:

A special meeting is being called to organize a PARENT SUPPORT GROUP at
_____ School.

DATE:

TIME:

PLACE:

PROBLEMS TO BE DISCUSSED:

WHAT SHOULD WE DO ABOUT THEM?

COME TO THE MEETING AND TELL US!

For further information call:

YOUR NAME

ADDRESS

PHONE

2. Put the date, time and meeting place in bold letters and center them or box them as shown in sample letter.
3. Sign your name, with address and phone number, so parents can call if they have any questions or need more information as shown in the sample letter.
4. Inform the school director or principal that you are organizing a parent support group and would like his/her cooperation. Ask for cooperation in sending out the notices. Do not be offended if the school refuses to send you a list. The school is required by law to keep such information confidential. But most

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- school officials will gladly send out the notices for you.
5. Ask that meeting notices be sent from the director's (or Principal's) office, with you providing the meeting notices, envelopes, stamps, etc....
 6. If the director or principal refuses, pass out the announcement at the next parent or PTA function.
 7. If your school has no such function, or if they are too infrequent, do a little detective work.
 - a. Find out from your child the names of as many classmates as he can remember, and approximately where they live. If he knows only one, you have a beginning.
 - b. You can call that parent, and ask if he/she knows other parents, if her child knows other children, etc, through a series of phone calls you can learn the identity of enough parents to call a meeting.

ORGANIZING A PARENT SUPPORT GROUP IN YOUR COMMUNITY

- I. Establish a Core Group to help you organize the Parent Support Group.
 - a. Place an ad in your local paper and write a letter to the editor, asking that other parents contact you to help organize a Parent Support Group.

Sample Letter

CALLING ALL PARENTS OF DEAF AND HARD OF HEARING CHILDREN:

If you are tired of promises and are ready for action, come to a special meeting to organize a Parent Support Group in our community.

DATE:
TIME:
PLACE:

PROBLEMS THAT MUST BE RESOLVED:

LET'S FIND SOLUTIONS LET'S PLAN A COURSE OF ACTION!

For further information call:

YOUR NAME:
ADDRESS:
PHONE:

- b. Call private schools for deaf and hard of Children, agencies in your area servicing deaf and hard of hearing children and ask them to send a representative to your

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organizing meeting.

- c. At the organizing meeting, make specific plans for a mass public meeting, assigning specific tasks, as outlined below.

A PUBLIC MEETING

Probably the best way to organize a parent support group is through a public meeting. A public meeting provides the means to reach parents you would never reach otherwise - those whose children are un-served and therefore cannot be reached through a public or private agency. It is those parents who need a parent support group most.

Purpose: To organize and activate parents in your community; to provide information; to seek specific suggestions and adopt a plan of action for the resolution of specific problems; reach parents throughout the community and ask their participation in a parent support group

Steps to Follow:

Before the Meeting:

1. Decide what issues will be covered at the meeting, examples:
 - A. Lack of services
 - B. Inadequate or inappropriate services
 - C. Lack of funds to provide quality service
2. Pick a catchy slogan to emphasize the issues
3. Set a meeting date, Allow at least one month preferably two or three months, from date of organizing meeting
4. Set meeting place. Pick a centrally located place easily accessible by public transportation. Churches, YMCA, youth centers and other public and private agencies usually have meeting space which is made available to organizations free or at nominal cost. Also try hotels, stores, shopping centers, banks, libraries, and other local businesses. Be sure the place is accessible to the physically handicapped.
5. Decide on a format: a panel, a workshop, or a speaker or two. Suggested format: a panel composed of those officials who are responsible for providing services for deaf and hard of hearing children. Example: (Board of Education personnel, special education department personnel, some legislators and/or congressmen, parents, a professional from the community) followed by questions from the audience.
6. Arrange for speakers. Call and ask them by phone, then immediately confirm by letter. (You can also reverse the process if you have enough time.)
7. Send special invitation letters (V.I.P. letters) to heads of private and public agencies, churches, state representatives, congressmen, and other appropriate VIP's

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Sample V.I.P. letter

Dear _____:

Because you are a leading citizen of our community, we are inviting you to attend a public meeting that could have a profound effect on the lives of our deaf and hard of hearing children. The meeting is about _____ and will be held on: (date and time) at: (Place).

Appearing on a panel will be: _____

We hope this meeting will bring together parents of deaf and hard of hearing children and others interested in their welfare for a concrete plan of action to obtain better services.

Won't you join us in this undertaking to provide better services for deaf and hard of hearing children?

Sincerely,

(Your Name and Signature)

8. Arrange for publicity through TV, radio, newspapers, school newsletter, etc.
9. Make arrangements for a literature table at the meeting, with literature from other Parent Support groups, private and public agencies, etc.
10. Do phone follow-up on agencies, to make sure their parents have been notified of the meeting, and that they are sending representatives.
11. Prepare a volunteer sheet for parents to volunteer for specific Jobs in your Parent Support Group.

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Sample Volunteer Sheet

(PLEASE FILL OUT WHETHER YOU ARE A PARENT, PROFESSIONAL OR VOLUNTEER.)

NAME _____

ADDRESS _____

CITY STATE ZIP _____

PHONE _____ Day _____ Night E-MAIL _____

AFFILIATION (PARENT, PROFESSIONAL, OR OTHER)

MY CHILD IS.

DEAF _____

HARD OF HEARING _____

VISUALLY HANDICAPPED _____

MULTIPLY HANDICAPPED _____

LEARNING DISABLED _____

PHYSICALLY HANDICAPPED _____

OTHER _____

I WOULD LIKE TO JOIN A PARENT SUPPORT GROUP _____

I ALREADY BELONG TO A PARENT GROUP _____

GROUP NAME _____

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PROBLEMS I WOULD LIKE A PARENT SUPPORT GROUP TO WORK ON:

I WOULD BE WILLING TO WORK ON:

LEGISLATION

PROGRAM

PUBLICITY

FUND RAISING

PROJECTS

MAILING CAMPAIGNS

RESEARCH PROJECTS

MEMBERSHIP

TYPING AND OTHER CLERICAL JOBS

SPECIAL PROBLEMS

DRIVING, PICK-UP SERVICE

OTHER

- 12 Set aside a specific time after speakers for questions from the audience. Be prepared with a list of your own if questions are slow in coming.
- 13 Prepare a plan of action to be proposed at the meeting.

At the Meeting

1. Appoint volunteer ushers for seating of panelists and taking care of their needs (fill water glasses etc....).
2. Appoint ushers to give directions to audience (to washrooms, parking lot, public telephones, etc.) and direct them to sign guest book and give volunteer sheets as they walk in.

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3. Appoint volunteers to collect volunteer sheets at the end of the meeting. (This is of crucial importance. You cannot have a parent support group if parents do not fill out volunteer sheets.)
4. Remind the audience, at the beginning and the end of the meeting, to fill out volunteer sheets.
5. Be sure to have questions and discussion from the audience.
6. Designate someone to propose a plan of action and ask support from the audience
7. Designate someone to announce the formation of our new Parent Support group with a suggested title. Ask for support from the audience for this action.
8. Announce the date of follow-up working meeting and urge all parents to attend to form Action Committees.

After the Meeting

1. Send thank you notes to all guest speakers.
2. Compile a file from guest book and volunteer sheets.
3. Set up appointments for personal visits to city and state officials and other public servants who attended the meeting to get their reaction, their cooperation in activities and proposals of your parent group.
4. Send notices to everyone who attended the meeting of follow-up working meetings.
5. Send out newsletter to everyone who attended the meeting, keeping them posted on all plans for action, asking for their participation and membership. Enclose sign-up volunteer sheet with checklist of all committees, membership form with return envelope.
6. Keep the press posted informing them of special committees formed; plans for action, etc. also try for TV and radio interviews, and newspaper features.

The next step is to set up some structure for your parent group: elect officers, set up committees, appoint committee chairpersons get by-laws, etc. described in the next chapter.

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THE NUTS AND BOLTS OF YOUR PARENT SUPPORT GROUP

Every organization needs nuts and bolts to keep it together. It needs officers a statement of goals and by-laws. It should obtain a state charter and a tax ID number. Every organization should also consider tax exemption status.

The first order of business at your first working meeting should be the election of temporary officers. Next, a nominating committee to select a permanent slate. Next, a statement of goals.

Your Parent Support group needs:

1. President or Chairperson (or Co-Chairpersons)
2. Vice-President or Vice-Chairperson
3. Recording Secretary
4. Corresponding Secretary
5. Treasurer

Also Committee Chairperson or Co-Chairpersons for some or all the following Committees:

1. Legislation Committee
2. Finance Committee
3. Membership Committee
4. Goals Committee
5. By-Laws Committee
6. Publicity Committee
7. Other Committees your group decides to set up

GOALS:

A goals statement is a written commitment by an organization to a set of goals, which the group will work to achieve.

Your parent support group should have both long-range and short-range goals. A brainstorming session during your first working meeting will bring them out. A goals committee should prepare a formal statement of the goals agreed upon during the brainstorming session. At a subsequent meeting, the goals should be formally adopted.

Aim high in your long-range goals. Adopt goals that will fulfill the needs of deaf and hard of hearing children in your community or city. Be more specific in your short-range goals, selecting goals that can be reached in a year or two through determined effort.

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BY-LAWS

By-laws are rules an organization agrees to live by. Your Parent Support group should have them to function smoothly and efficiently. By-Laws are particularly necessary if there is any dissension within a group (and some dissension is bound to happen sooner or later). The dissension and possible damage can be kept to a minimum if the rules are spelled out in written By-Laws.

Most organizations have the same basic rules; hence their By-Laws are essentially the same. Keep yours short, simple and to the point. By-Laws are at the end of this manual. You may use them as a guide if you wish.

STATE CHARTER

A state charter is a state document verifying the existence of your organization. It's a good idea for any parent group to get one. It's a necessity if you intend to do major fund-raising, lobbying, etc.

Simply write to: Secretary of State, State Capitol Building Sacramento, Ca.

REGISTRATION AS A NON-PROFIT ORGANIZATION

If you are going to solicit funds as a non-profit organization, you should also register your Parent Support group with your state Attorney General's Office.

Simply write to:

TAX EXEMPTION

Attorney General 's Office
State Capitol Building
Sacramento, Ca.

If your Parent Support group wants to do major fund-raising, solicit businesses, foundations? etc., getting a tax exemption from the Internal Revenue Service is a must.

Steps to follow

1. Get several copies of form 1023 from your local Internal Revenue Office
2. Have them filled out by a lawyer. (This is important, as proper terminology must be used.) You can contact a local legal aid clinic for free legal help on this.

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3. Remember that the I.R.S. is forbidden to give a tax exemption to organizations that engage in substantial lobbying. Therefore, lobbying activities must appear minimal on your application. You should stress your group's educational activities.

AFFILIATING WITH CITY STATE. AND NATIONAL ORGANIZATIONS

When your Parent Support group is well established you may wish to affiliate with a large organization for maximum power. Among the organizations you can affiliate with are:

1. IMPACT
2. AMERICAN SOCIETY FOR DEAF CHILDREN
3. ALEXANDER GRAHAM BELL ASSOCIATION CALIFORNIA CHAPTER

Steps to follow:

1. Write a letter to the organization you wish to affiliate with, expressing your desire to affiliate, and asking for all necessary forms.
2. Appoint or ask for volunteers to act as delegates to the organization.

An affiliation with a city or state chapter generally brings automatic membership in the national chapter. Find out from your local association.

Hazards to watch out for in affiliation:

1. Make sure your Parent Support group will not have to sacrifice any of its goals.
2. Check the organization's goals carefully and the means they have adopted to reach them. Consider whether they will slow you down or speed you up.
3. Make sure your Parent Support group does not lose its autonomy: the ability to make policy-making decisions and the ability to act without consulting the association.
4. Make sure your Parent Support group does not give up more than it loses in time, energy, money, and power.

If an affiliation gives your Parent Support group more power, by all means affiliate. If your group has to give up power, don't affiliate. Continue to make it on your own. Continue to make your own power.

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MEMBERSHIP

The strength of your Parent Support group depends on its membership. Keep your Parent Support group strong by having an active membership committee, who will do the following:

1. Set up a schedule of membership dues. Suggested dues: \$5-10 for individual or family membership \$15 for contributing membership \$25 for "Angels", and \$100 Lifetime membership.
2. Send a letter on your organization letterhead inviting everyone who attended your public meeting to join your Parent Support group. Include a membership form, volunteer sheet and self-addressed return envelope.

Sample Letter

Dear _____,

A new Parent Support group was born at a public meeting
at _____ (Date of your meeting).

The new group is called- (Your Parent Support group's name). We have exciting plans: (list them).

Won't you join us in this new undertaking and become a member

of _____

Dues are _____ per year.

(Signed by your Temporary Officers with their phone numbers.)

3. Enclose membership letter, form and return envelope in every mailing your group sends out.
4. Hold annual membership drives, assigning present members to personally contact potential members to join your parent support group.
5. Have a membership table at every parent support group function, and functions of other appropriate groups (with permission of that organization).

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TO KEEP YOUR PARENT GROUP FROM DEATH'S DOOR

After a parent support group has been organized, the main problem is to keep it alive and well.

A parent support group is generally organized to deal with a specific problem, usually a crisis. After the crisis is over, or the problem has been resolved, interest often gradually wanes until the group finds itself at death's door.

The death of a parent support group usually comes from apathy and lack of interest. But it may also be the result of a deliberate plan. When the specific purpose for the formation of the group has been accomplished, when the problem has been resolved, it seems pointless to many parents to keep the group going.

Keeping a group going requires a lot of time, work, energy, and often money. Why continue to have meetings and do all that hard work when there is no reason?

But there is a reason.

There are many reasons.

1. A dead parent support group cannot act in a crisis. Your parent support group will have to go through the time-consuming, money-consuming process of organizing all over again the next time you have a crisis.
2. A dead parent support group cannot prevent a crisis. But a live one can. Crises usually happen when no one is watching. A parent support group serves as a continual reminder to bureaucracies that someone is watching - and they will react accordingly. A parent support group, which is alive and active, will see the crisis coming - and will be able to act and stop it in time.
3. A live parent support group can quickly reverse the tide once a crisis has hit and minimize its effects.

Keeping a parent support group alive is often harder than starting one. Breathing life into a dying parent support group is even harder. Plan to keep your parent support group from death's door while it is still young, still spirited, and vigorous.

WAYS TO KEEP YOUR PARENT SUPPORT GROUP ALIVE AND WELL

1. Get a new focus, new problems to tackle to replace the one which was the

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springboard for your group. You won't have to look long. There are plenty of problems in your community, your city, and your state.

2. Take on a special project that has long been needed, but which no organization has yet been willing to tackle.

Suggested projects:

- a. A directory of services for your area (city, state), categorizing all existing services for all categories of deaf and hard of hearing children and adults. No money is needed for this, except an initial investment to cover the cost of the mailings and first printing. Figure out all costs (costs of printing, mailing, etc.) and charge double. You will probably wind up just breaking even.
 - b. A booklet describing the legal rights of parents - what they are entitled to in education for their children. Public aid, income tax deductions, social security, 551, etc.
 - c. A Parent Rights Training Program, to train parents on IDEA.
 - d. Legislative tour of state institutions.
 - e. Baby-sitting co-op where parents exchange sitting.
3. Continue to have regular meetings (at least once a month) even if only officers show up. Regular meetings keep the machinery of your parent support group well oiled and ready for action in a crisis. Regular meetings enable you to keep your membership informed on issues, and to be prepared for action whenever necessary.
 4. Have an open door policy. Welcome anyone interested in your group's efforts, rich or poor; white, yellow, or red; professionals and non-professionals; parents and non-parents; conservatives, radicals, and anyone in between. Talent and hard work pops up in unexpected places. If you welcome everyone, your parent support group will not lose out in its reach for talent and workers.
 5. Function democratically - not as a social club. Make all your meetings open meetings, including board meetings (after all, what do you have to hide?)
 6. Have an active membership committee, continually seeking new members.
 7. Stay abreast and up to date on all action by local bureaucracies. Send a representative to their meetings (Meetings of all public agencies must be public by law). Obtain copies of all minutes and transactions (it is required by law that the public be allowed to see minutes and transactions. For copies, you may be charged a small fee.)

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8. Keep the press informed of all-important activities. This will let them know you're still around, and they will be more likely to remember your group and give you coverage when publicity is crucial.
9. Don't become a "paper organization"- one that limits itself to making statements, writing letters, etc. Adopt a course of action and follow it.
10. Don't become just a fund raising group, a group that raises money for parties, trips, games, etc. Fund raising is necessary, and trips, parties, games, etc. are fine. But don't limit your parent power to just that. The majority of your parent support group's time should be spent on moving bureaucracies, to force them to fulfill their responsibilities. Remember you wouldn't need to raise funds if the bureaucracies were really doing their job.
11. Don't let your parent support group become just a Gripe Group. Gripe sessions are useful to pinpoint what is needed, but griping should have a specific purpose: to plan a course of action that will eliminate the problem. Insist that every gripe be followed by a specific proposal for action.
12. Don't let bureaucracies use the "Divide and Conquer" technique on your group. Cooperate; work with other groups whenever you can. Co-ordinate your activities for maximum results. Don't become angry with a group because it assumes a project you had always considered your domain. Offer to help the group with the project. If you decide your participation is not needed, start another project.
13. Cooperate with private and public agencies. But don't sacrifice your goals for the sake of "cooperation".
14. Remember that the purpose of your parent support group is to improve services for deaf and hard of hearing children, not to provide ego satisfaction to members. There is nothing wrong with deriving ego satisfaction out of the work done through the parent support group. But the ego satisfaction should be a by-product, not the main purpose. If a parent's ego is satisfied at the cost of services, then it *is* detrimental to the group.
15. Share the glory that comes to your parent support group. Don't let only a selected few appear on television, radio, and newspaper interviews. Get as many parents involved as possible.
16. Don't be concerned only with the welfare of the children in your organization. Take a universal approach, and work toward the welfare of all deaf and hard of hearing children. Your child will wind up getting more in the long run.
17. Communicate with your membership on a continual basis. Keep your parents informed through monthly reports, newsletters, and appropriate reports at all activities.
18. Keep your members involved. Give them new responsibilities appropriate to their

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skills and talents. Encourage them to develop new skills (such as public speaking, writing, newsletter editor) and provide appropriate training for this.

The following is a sample of a by-laws document. Your organization may make many necessary changes to achieve your goals.

BY- LAWS

NAME OF PARENT SUPPORT GROUP

ARTICLE I – Name

The name of this organization shall be the_____

ARTICLE II - Purpose

The purpose of this organization shall be to obtain better services for all deaf and hard of hearing children through advocacy, public education, referral, and special services.

ARTICLE III - Affiliation, Membership and Dues

The _____ is an organization of parents of deaf and hard of hearing children, concerned citizens, and organizations of parents or professionals serving deaf and hard of hearing children. Any organization, individual, or family subscribing to the goals of _____ may become affiliated through membership.

Membership dues for a family or individual shall be \$XX.xx per year. Organizational membership dues are \$XX.xx per year or some higher amount.

Membership entitles a member to all mailings, monthly newsletter, meeting notices, the right to attend meetings and to vote for officers at the Annual Election Meeting. A person or organization wishing to subscribe to the monthly newsletter but not participate in other activities may do so for a subscription fee of \$XX.xx. Other informative booklets can be obtained for a nominal cost.

ARTICLE IV - Officers, Board of Directors and Nominating Committee

Section A – Officers

Officer's of _____ shall be:

President
Vice President
Secretary

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Treasurer

The officers shall serve for a term of one year and shall be elected at the _____ Election meeting.

Section B - Board of Directors

The Board of Directors shall consist of the officers and the committee chairpersons of all standing or special committees. The standing committees of the organization shall include:

Membership
Finance
Legislative
Publicity
Education

The Board of Directors as needed shall establish special committees.

Duties of the Board of Directors

The Board of Directors shall be responsible for overseeing the functioning of _____, shall participate in the selection and supervision of staff members, shall develop programs to accomplish the goals of the committees, and shall attend monthly Board of Directors' meetings.

Voting

Each member of the Board of Directors shall have one vote, except the President who shall vote only in the case of a tie.

Removal

A Board member may be removed for gross neglect of duty (Including three consecutive unexcused absences from Board meetings) by majority vote of the Board of Directors. Thirty days' notice must be given to any Board member before a vote for removal can be taken.

Vacancies

The President and Vice President shall be empowered to fill any vacancies in the Board of Directors with the approval of the majority of the remaining Board members

Section C - Nominating Committee

The Nominating Committee composed of five members at least two of who are not currently officers. The Committee shall be appointed by the Board at the _____ meeting to nominate officers and committee chairpersons. The report of the Nominating Committee shall be published in the newsletter prior to the (date) _____ Election Meeting.

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ARTICLE V - Meetings Section A - Regular Meetings

Regular meetings of the Board of Directors shall be held the first week of every month except by special arrangement of the officers.

Section B - Quorum

Five members of the Board of Directors shall constitute a quorum.

Section C - Special Meetings

Special meetings of the Board of Directors or the membership to discuss and take action on emergencies shall be called by arrangement of the officers.

Section D - Election Meeting

All members shall be invited to attend the _____ Election Meeting of the Board of Directors. At this meeting officers shall be elected by majority vote of the membership. Announcement of the Election Meeting, including the report of the Nominating Committee and an invitation to the membership to attend shall be published in the newsletter thirty days in advance of the meeting. Additional nominations shall be accepted if the names of the nominees and their qualifications are submitted in writing at least two weeks prior to the _____ Meeting.

ARTICLE VI - Finances

The fiscal year of the organization shall be from January 1 to December 31.

Section A - Disbursement of Funds

The funds of this organization shall be deposited in a bank selected by the Treasurer with the approval of the President. All financial obligations of the organization shall be discharged by check on approval of the President and signed by any two of the following:

President
Vice President
Treasurer

Section B - Annual Report

The President and Vice President shall submit an Annual Report, including a complete financial statement, to the State of California in accordance with state laws.

Section C - Dissolution

In the event of dissolution of the organization, all assets remaining after all liabilities have been met shall be distributed to one or more not-for-profit organizations serving deaf and hard of hearing children selected by the Board of Directors.

Article VII - Amendments

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These By-laws may be amended at any regular meeting of this organization by an affirmative vote of two-thirds of the members present. Advance announcement of any proposed changes and an invitation to members to attend the meeting and vote must be made in the preceding monthly newsletter.