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#### ABSTRACT

This easy-to-read booklet for parents of handicapped children, contains information on how to organize parent groups to move bureaucracies toward providing better services for handicapped children. Included are suggestions for choosing effective leaders, lobbying for results, using various media, setting up classes in public schools or starting a private school, organizing a coalition, providing funds, and keeping the group together. Sample letters and numerous practical suggestions are given. Information on the Co-ordinating Council for Handicapped Children, a volunteer organization concerned with the special needs of handicapped children, is provided. (ED)

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## HOW TO ORGANIZE AN EFFECTIVE PARENT GROUP

## AND MOVE BUREAUCRACIES

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# HOW TO ORGANIZE AN EFFECTIVE PARENT GROUP AND MOVE BUREAUCRACIES

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#### PREFACE

This booklet is written specifically for parents of handicapped children and their helpers to show them how to move bureaucracies and get better services for their children.

Others will find it equally useful, even though they may not be especially concerned with the needs of the handicapped.

Many of the techniques and strategies described in this booklet have been used successfully by organizations servicing mainly the non-handicapped.

But few parent groups have. Few have dared to push enough; few have dared to risk offending bureaucracies to reach their goals.

Yet parents of handicapped children have enormous power. Handicapped children make up more than 10% of the school population, according to figures from the Health, Education, and Welfare Department. Their parents number 30 to 40 million.

With all this parent power, why are services for the handicapped a rock bottom priority in this country? We believe-because parents have never really used their power.

We hope this booklet will wake up the parent power that lies dormant throughout this country. We hope it will act as a catalyst in the creation of new parent groups and in the metamorphosis of old ones.

We hope it will inspire parents to change an ineffective parent group into an action group, or to leave it if there is no hope, and start a new one.

We hope it will move bureaucracies and make services for handicapped children a top priority in this country.



#### INTRODUCTION

Caring is power. Sharing is power. Parents working together is power.

The Co-Ordinating Council for Handicapped Children has one goal--to help parents mobilize their caring and sharing powers into action to help all handicapped children.

The needs of the children are great--especially for medical treatment and educational training. Their needs have been responsibly recognized but not met, by society.

Parent power means lobbying for your child and all handicapped children. Effective lobbying can only take place through organized groups.

There cannot be further compromise with the lives of children due to insensitive and inadequate responses.

Parents must organize and demand action to gain and improve services which are so desperately needed.

Parent power--speak, unite, lobby, picket, march. Act NOW. Only you can represent your child.

Barbara Rice, Assistant
Professor
Graduate School of Social Work
Rutgers-the State University
New Brunswick, New Jersey



# HOW TO ORGANIZE AN EFFECTIVE PARENT GROUP

#### AND MOVE BUREAUCRACIES

#### CHAPTER I

## WHY A PARENT GROUP?

There are many reasons for a parent group. What they amount to is: to help you help your handicapped child; to help you help yourself.

# A parent group can give you power to:

- get those services your handicapped child is legally entitled to.
- get legislation passed to provide those services your child needs which are not yet proving by law.
- get better services fil public and private agencies.
- open a school, day care center, recreational program, worlshop, public school special classroom, or any other program your child needs.

# A parent group can also help you:

- get the encouragement and comfort you need to help your child.
- 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 with better schools, better work opportunities, better housing, and better care all around.

You may feel the need to organize a parent 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 group can help you get it.

## PARENT POWER

A parent group can help you develop parent power, the power you can have as a voter, a lobbyist, a pressure group - if it is harnessed and joined with the power of hundreds, of thousands of other parents like yourself.

One parent, alone, can do a lot if she is determined enough and willing to work hard enough to get what she is after. 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.

#### CHAPTER II

# ORGANIZING AN EFFECTIVE PARENT GROUP

You may say: "What? Me? I've never organized anything in my life!"

You can still organize a parent group - and move bureaucracies - if you want to badly enough. If your child needs it badly enough. And if you are willing to follow the instructions in this manual.

To organize a parent group at the special school your child attends - or at the public school where your child is in a special classroom, follow these steps:

1. Write a letter to all the parents (this can be a form letter which you mimeograph or have maroxed, or it can be a personal letter), announcing a meeting to form a parent group. Tell them why you feel a parent 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 group to carry them out.

# Sample Letter

CALLING ALL PARENTS OF HANDICAPPED CHILDREN!

A	special meeting	is being	called	to	erganise
a	PARENT 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	
ADDRI	ess _	
PHONE	3 —	

- Put the date, time, and meeting place in hold letters and center them or box them as shown in sample letter.
- 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 group and would like his (her) cooperation. Ask for a list of parents to send out notices. (Do not be offended if you are refused. Most schools insist on keeping such information confidential.)
- 5. If you are refused a list of parents, 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 still refuses, pass out the letter at the next parent or PTA function.
- 7. If your school has no such functions, 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 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 GROUP IN YOUR COMMUNITY

- 1. Establish a Core Group to help you organize the parent 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 group.

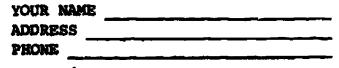
## SAMPLE AD

CALLING ALL PARENTS OF HANDICAPPED CHILDREN.

If you are tire, of promises and are ready for action, come to a special meeting to organize a parent group in our community.

DATE.

TIME: PLACE:								
PROBLEMS 7	THAT	Must	BE	RESOLVI	<b>即:</b>			
LET'S FINE ACTION!	) SOI	UTIO	vs:	LET'S	PLAN	A	COURSE	OF





For further information call:

- b. Call private schools for handicapped children, agencies in your area servicing handicapped children and ask them to send a representative to your organizing meeting.
- c. At the organizing meeting, make specific plans for a mass public meeting, assigning specific tasks, as outlined below.

  (Organizing a Public Meeting)

# ORGANIZING A PUBLIC MEETING

Probably the best way to organize a parent group is through a public meeting. A public meeting provides the means to reach parents you would never reach otherwise - those whose children are unserved and therefore cannot be reached through a public or private agency. It is those parents who need a parent group the 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; to reach parents throughout the community and ask their participation in a parent group.

# Steps to Follow: Before the Meeting:

- 1. Decide what issues will be covered at the meeting.
  - a. lack of facilities
  - b. poor facilities
  - c. lack of funds
- 2. Pick a catchy slogan to emphasize the issues.
- Set a meeting date. Allow at least one month, preferably two 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, hotels, stores, shopping centers, and other local businesses.



- 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 handicapped children (Board of Education personnel, mental health department personnel, etc...also some legislators and/or congressmen, a parent, 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 could also reverse the process: write a letter, then call, then write a letter of confirmation.)
- 7. Send special invitation letters (V.I.P. letters) to heads of private and public agencies, churches, state representatives, congressmen, and other appropriate V.I.P.'s.

SAMPLE V.I.P.	LETTER
---------------	--------

Dear	
Because you are a leading citizen	of our com-
munity, we are inviting you to att	end a public
meeting that could have a profound	effect on
the lives of our handicapped child	
	(time)
This meeting will be held on:	(date)
At:	(place)

Appearing on a panel will be:

We hope this meeting will bring together parents of handicapped 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 handicapped children?

Sincerely,

(Your Name & Signature)

8. Arrange for publicity. See Chapter X "How to Make Headlines".



- 9. Make ar ingements for a literature table at the meeting, with literature from other parent 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 group.

#### SAMPLE VOLUNTEER SHEET

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

NAME		
ADDRESS		
CITY		ZIP
PHONE		
AFFILIATION (PARENT, PROFI	ESSIONAL, OR OTHER)	
MY CHILD IS: RETARDED	EMOTIONALLY DIST	URBED
BLIND PARTIALLY SEEIN	NG DEAF HI	EARING IM-
PAIRED SPEECH HANDICA	APPED MULTIPLE	HANDI-
CAPPED HAS LEARNING D	DISABILITIES OF	THER
I WOULD LIKE TO JOIN A PAR	RENT GROUP	I ALREADY
BELONG TO A PARENT GROUP	(NAME)	
PROBLEMS I WOULD LIKE A PA		
I WOULD BE WILLING TO WORK	ON: LEGISLATION I	PROGRAM
FUND RAISING PROJECTS	MAILING CAMPAIGNS	MEMBER-
SHIP TYPING AND OTHER	CLERICAL JOBS	RESEARCH
PROJECTS PUBLICITY	DRIVING, PICK UP	SERVICE
SPECIAL PROBLEMS OTHE	R	



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

## AT THE MEETING

- 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 guestbook and give volunteer sheets as they walk in.
- 3. Appoint volunteers to collect volunteer sheets at the end of the meeting. (This is of crucial importance. You cannot have a parent 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 your new parent group with a suggested title. Ask for support from the audience for this action.
- 8. Announce 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 check list 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. (See Chapter X, "How To Make Headlines")

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

#### CHAPTER III

# THE NUTS AND BOLTS OF YOUR PARENT GROUP

Every organization needs nuts and bolts to keep it together. It needs officers, a statement of goals, by-laws. Every organization should also consider obtaining a state charter and a 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 group needs:

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



Also, Committee Chairman or Co-Chairmen for 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. (See Chapter VI, "How To Make Your Parent Group An Action Group".)

Your parent group should have both long-range and short-range goals. A bull 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 bull session. At a subsequent meeting the goals should be formally adopted.

Aim high in your long-range goals. Adopt goals that will fulfill all the needs of handicapped 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.

# BY-LAWS

By-Laws are rules an organization agrees to live by. Your parent 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. CCHC 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...

Sim ly write to: Secretary of State
State Capitol Building
(Your state Capital and State)

# REGISTRATION AS A NON-PROFIT ORGANIZATION

If you are going to solicit funds as a non-profit organization, you should also register your parent group with your local U. S. Attorney General's Office.

Simply write to: U. S. Attorney General's Office State Capitol Building (Your state Capital and State)

#### TAX EXEMPTION

If your parent group wants to do major fund-raising, solicit business, 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 your local OEO(Office of Economic Opportunity) legal aid clinic for free legal help on this.
- 3. Remember that the I.R.S. is forbidden to give a a tax exemption to lobbying organizations. Therefore, lobbying activities must appear minimal on your application. Your should stress your group's educational activities.

# AFFILIATING WITH CITY, STATE, AND NATIONAL ORGANIZATIONS

When your parent group is well established, you may wish



to affiliate with a large organization for maximum power. Among the organizations you can affiliate with are:

- Your local, state, and national association for retarded children.
- Your local, state, and national association for children with learning disabilities.
- Your local, state, and national association for autistic children.
- 4. Your local, state, and national association for spina bifida children.
- 5. Your local, state, and national association for cerebral palsy children.
- Your local, state, and national association for hearing-impaired children.
- 7. Your local, state, and national association for speech-impaired children.
- 8. The Co-Ordinating Council for Handicapped Children

## STEPS TO FOLLOW

- Write a letter to the organization you wish to affiliate with, expressing your desire to affiliate, and asking for all necessary forms.
- 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 OUR FOR IN AFFILIATING

- Make sure your parent group will not have to sacrifice any of its goals.
- Check the organizations' 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 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 group does not give up more than it loses - in time, energy, money, and power.

If an affiliation gives your parent 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.

## MEMBERSHIP

CHARLE TERRIBE

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

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

Shuring lefter:	
Dear	
A new parent group was born on public meeting) at (place	(date of your of your meeting)
The new group is called	(your parent
group's name). We have many exciting pla	(list them).
Won't you join us in this new undertaking mamber of Dues are	g and become a s \$ per year.



numbers.)

(Signed by your Temporary Officers with their phone

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

#### CHAPTER IV

## CHOOSING EFFECTIVE LEADERS

Many organizations, having successfully gone through the birth pangs of organizing, make a crucial error when they become formalized. When it is time to pick leaders, it is decided that the organization needs some experts, some professionals, some business leaders and prestigious members of the community.

Those who have done the drudge work, who have worked long hours getting the group started, even those who have played a crucial role in organizing the group are often by-passed as "amateurs", "inexperienced", "not well-known", etc...

The Board of Directors soon becomes top-heavy with experts, psychologists, psychiatrists, social workers, special school directors, business leaders, Board of Education personnel, mental health personnel, and the parent group ceases to be a parent group.

If the experts are also non-doers, they can actually threaten the life of the parent group. They are often too busy to undertake any project or any of the time-consuming chores that constantly need doing in any organization. They cry "militant" whenever an action program is proposed, and one proposal after another is killed.

These non-doers will adopt a policy that keeps your parent group from moving ahead and slowly lead it to death's door.



If a professional, business leader, or community leader has assumed a major role in organizing your parent group or otherwise shown his dedication to your group's goals, by all means ask him to be a board member. But don't ask him simply because he is a professional, or business leader, or community leader. That in itself does not qualify him as a parent group leader.

Leaders should be picked on the basis of their ability to lead, their devotion to the group and its goals. Those who are most qualified are those who have already assumed a leadership role in the organizing of your parent group, who have already shown their dedication and support of its goals.

The majority of board members of a parent group should be parents - for the simple reason that a parent group cannot remain a parent group without parent leadership.

# WHAT MAKES AN EFFECTIVE PARENT GROUP LEADER

- 1. real dedication to the group and its goals
- ability to motivate members to aim higher in their goals, and to move forward at a rapid rate to reach them
- 3. ability to motivate members to accomplish the dozens of tedious chores which keep an organization moving
- ability to delegate instead of doing everything himself and turning the organization into a one-man show
- 5. ability to become enthusiastic over other members' ideas and proposals and push them through (not just his own)
- ability to accept responsibility and blame when things go wrong, and work to correct the problem instead of wasting time blaming others
- 7. ability to negotiate with bureaucracies and win major concessions



- 8. ability to remain undeterred by intimidation either by threats, friendliness, or flattery
- 9. persistence, determination to see a problem through
- 10. courage to adopt and push through an unpopular stand to reach the group's goals
- 11. ability to place the group's goals above personal goals and ambition
- 12. ability to communicate with the membership both on a personal level with individual members, and on a more impersonal level through
  necessary reports (treasurer's reports, reports of various activities, etc...)

#### CHAPTER V

#### UNCOVERING BURIED TALENT

There's buried talent in every parent group - talent that just lies there, waiting for someone to uncover it. Sometimes people are frank and open and don't mind admitting that they have talent and special skills. But usually people are shy about saying anything good about themselves. So it falls on the parent group leadership to take on the task of uncovering buried talent among their membership.

What kind of talent and special skills does a parent group need? It needs:

- 1. fund raisers
- publicists
- 3. writers
- 4. artists
- 5. photographers
- 6. lawyers
- 7. researchers
- 8. promoters
- 9. organizers
- 10. public speakers
- 11. administrators
- 12. lobbyists



It also needs a lot of hard working clerical help - typists, envelope addressers, mail stuffers, fillers, phone callers, drivers.

Perhaps some of your parents have worked in some of the above capacities during their working years. Perhaps they have never done paid work in these areas, but have skills and would like to volunteer them.

Don't overlook the non-professionals and the non-college graduates in your search for talent. These are often more dependable than professionals and will consider their job assignment a real challenge. They will take great pride in their work and will take special pains to make every project a major achievement.

Don't hesitate to assign an important project to an inexperienced parent who has indicated real interest in the job. Assign an experienced person to work with her until she has mastered the skills involved. Encourage her new ideas, her innovative ways of doing things. Compliment her on her progress, but do not be afraid to point out errors. This is necessary if she is to become proficient. Be gentle and patient and try to couple criticisms with compliments.

Always look for buried talent in your own organization before asking someone from the outside who has never been involved in your group to undertake a major project. It's generally bad for group morale to have an important job assigned to an outsider before a serious attempt has been made to get someone within the parent group to undertake it.

There are several questions that should be asked when an outsider is asked to fill an important position in your group:

- 1. Is he interested only in the job itself, or is he also interested in the reason behind the job (to promote the interest of the parent group in some way)?
- 2. Is he committed to your group'sgoals, or is he indifferent or opposed to them?



- 3. Is he committed to action as a means of achieving your group's goals, or is he opposed to such "militancy"?
- 4. Is he willing to work with the group, or is he interested only in making decisions and handing orders down?

Every organization should constantly be involving new people, but before they are assigned new projects or given leadership positions, there should be no question that they are committed to the goals of the organization and in general agreement with the means you choose to obtain them.

# HOW TO UNCOVER BURIED TALENT IN YOUR ORGANIZATION

- Prepare a questionnaire designed to uncover the buried talent in your parent group.
  - a. List all the talents and special skills your group needs, with a blank space for parents to indicate they wish to fill these positions.
  - b. Have a special spot for parents to list what special skills they have (not listed on the questionnaire) which they would like to volunteer.
- Ask for volunteers at meetings for positions you need to fill - instead of merely appointing people for them.
- 3. Ask members if they know other members who have special talents and special skills.
- 4. Place an ad in your group's newsletters listing skills needed.
- 5. Ask members to include their families and friends in all your parent's group activities.
- 6. Use handicapped children as much as possible for jobs within their abilities - mailing, filing, mimeographing, clean-up jobs, errands, etc...



#### CHAPTER VI

#### MAKING YOUR PARENT GROUP AN ACTION GROUP

To move bureaucracies, your parent group must be an action group.

To make your parent group an ACTION GROUP, determine what the unmet needs are in your school, your community, your city, your state. Decide what your goals should be both long range and short range goals.

Decide what specific needs or problems you want to work on - and work out a plan of action to reach your goals.

## Your plan of action can be:

- Opening a special school for handicapped children (see Chapter XII, "How To Open A School and Get Funding for It").
- Opening a special education classroom in your local public school (see Chapter XI, "Opening A Classroom in A Public School").
- 3. Opening a day care center in your community (see Chapters XI and XII).
- 4. Setting up a recreation program for handicapped children in your community (see Chapters XI & XII).
- 5. Opening a workshop for adolescent handicapped adults (see Chapters XI and XII).
- 6. Better state institutions for handicapped children.
- 7. Better employment opportunities for handicapped adults.
- 8. Better legislation for the handicapped (see Chapter VIII, "How To Lobby and Get Results").
- 9. Proper enforcement of your local building code to prevent lead poisoning, a leading cause of mental retardation.
- 10. Getting teacher aids for public school special education classrooms.



- 11. Getting better teachers for public and private schools (also change in teachers where warranted).
- 12. Getting special equipment for public and private schools.
- 13. Getting better transportation service.
- 14. Getting more and better counselors, psychologists, social workers, diagnosticians, etc.
- 15. All of the above.

You can carry through your plan of action by utilizing the following strategies:

- 1. a registration drive of handicapped children
- a march on your local board of education, mental health department, city hall, state legislature, etc...
- 3. a public rally
- 4. a sit-in
- 5. a boycott
- 6. a teach-in
- 7. a camp-in
- a mail campaign (see Chapter VIII, "How To Lobby and Get Results")
- 9. a telephone campaign (see Chapter VIII)
- 10. A telegram campaign (see Chapter VIII)
- 11. a public hearing
- 12. a bus or car cavalcade
- 13. picketing

The purpose of these strategies is to bring your problem to the attention of the public and thereby exert enough pressure on bureaucracies to carry out the changes you want. The strategies also inform bureaucracies that you mean business, that you will not stop the pressure until the problem is matisfactorily resolved.



# ORGANIZING A REGISTRATION DRIVE

Purpose: \*to notify local and state officials of the number of handicapped children from your community (city, state) who need services, and to register them for educational and other benefits they are entitled to by law.

- \*to inform parents of benefits their children are entitled to and the necessary steps they must take to obtain them.
- \*to focus public attention on the lack of facilities for handicapped children.
- \*to mobilize parents to improve services for handicapped children.
- \*to identify parents of handicapped children who may be potential members of your parent group.

#### STEPS TO FOLLOW

- 1. Ask your local school board, your local public and private agencies to co-sponsor the registration drive.
  - a. Send out a letter to these groups (make it a personal letter if you can), with return envelope for their reply.
  - b. Phone those agencies which haven't replied in time allotted and urge them to participate.

(Do not be deterred if your local school board refuses to participate, giving the usual excuses of lack of time, lack of money, lack of staff, etc... When the Council sponsored a mass registration drive in 1969, the Board of Education refused to participate. When the Council went ahead, and mimeographed and distributed 60,000 flyers, the Board did a complete turnabout and announced a month-long registration drive to coincide with the Council's one-week drive.)

 Make arrangements for publicity. See Chapter IX, "How To Make Headlines".



3. Make sure you order enough flyers to cover every child in every special school, every public school, every public agency, every hospital, every church, every store and shopping center. (See Chapter IX, "How To Make Headlines".)

Put a poster in every store window, every agency, every church; also on trees and lamp posts - particularly on street corners, at bus stops, in front of churches, shopping centers, stores and other places of heavy traffic.

- 4. Have the flyer list the names and phone numbers of at least four people who can be called by people who need more information.
- 5. Keep a record of every phone call, with names, addresses, phone numbers and other information the parent gives you. These names will be among your likeliest prospects for your parent group.
- 6. Set up a booth in your local shopping center the Saturday before the registration drive begins. Have at least two volunteers manning the booths at all times, on two or three hour shifts. Make the booth as attractive as you can, with posters, art work, decorations, etc... Have a large donation can prominently displayed. Also have membership forms handy for people to join your parent group. Hand out flyers from the booth to everyone who passes by.

# ORGANIZING A MARCH

Purpose: \*to focus public attention on the lack of facilities for handicapped children.

- \*to mobilize parents, professionals, and other concerned citizens to improve services for handicapped children.
- \*to identify parents of handicapped children who may be potential members of your parent group.



#### STEPS TO FOLLOW

- 1. Follow the same steps outlined for registration drive above.
- Get your co-sponsors solidly committed to bringing at least ten people each. Phone them 2 weeks and 5 days before the march for a tally.
- 3. Assign marshals to keep order and keep line moving during the march (one from each co-sponsor would be a good arrangement).
- Sign up speakers at least a month ahead. Call and ask them, then confirm arrangements by letter.
- 5. Designate a spokesman (the head of your parent group or the chairman of the march or both) for the press, and the bureaucracy you are marching against.
- Meet with the spokesman beforehand to prepare him for his press appearance and encounter with the bureaucracy.
  - a. Have a prepared statement, stating your grievances and demands. The spokesman should not confine his remarks to the statement. He should use it as a guide for himself in his presentation, and to hand out to the press and public officials.
  - b. Prepare a list of questions likely to come up from the press and public officials, and have answers, data, etc... ready.
- 7. Prepare picket signs, banners, etc... with catchy slogans.
- 8. Get buttons or home-made cut-ours with snappy slogans which identifies your group and its goals. Ex. "No More Cuts in Special Education"; "Children Before Bureaucracies"; "Handicapped Children Need an Education Too".
- 9. Have legal help on stand-by.



#### ORGANIZING A RALLY

Purpose: Same as for the march.

#### STEPS TO FOLLOW

Same as for the registration drive and the march.

## ORGANIZING A SIT-IN

Purpose: To win a specific objective.

## Examples:

\*Set up a meeting with an official who refuses to meet with your group.

\*Get children enrolled in school.

- \*Collect papers which a bureaucracy has been slow in processing.
- \*Collect overdue tuition payments to special schools (where state law allows tuition to special schools).
- \*Get a written commitment from a bureaucracy to a specific course of action.

# STEPS TO FOLLOW

- 1. Follow all steps outlined in organizing a registration drive and organizing a march.
- Be prepared to spend the day. Bring the children all of them, from toddlers on up, handicapped and non-handicapped.
- 3. Bring all necessary equipment: food, baby bottles, diapers, toys, etc...
- 4. Let children behave generally as if they were at home. Do not stop them from playing, making noise, etc... simply because this behavior disrupts office routine. The more disruption, the sooner you will get what You are after.



- 5. Have a prepared list of demands and do not leave until you get what you are after.
- 6. Make all arrangements for publicity. Follow steps in Chapter IX, "How To Make Headlines".
- 7. Have extra cars on hand for transportation of children for emergency purposes.
- 8. Have legal help on stand-by.

(The Council organized a Sit-In in 1969 to collect 5 months' overdue tuition to special schools. Checks were out in 24 hours.)

# ORGANIZING A BOYCOTT

- Purpose: 1. to publicize a specific problem
  - a. the number of children in need of special education facilities
  - b. poor quality of a specific special education program
  - c. bad conditions in a state institution
  - d. poor quality of any service for handicapped children
  - 2. to win a specific objective
    - a. open a special education classroom in a public school
    - b. prevent scheduled closing of a specific program for handicapped children
    - c. improve quality of specific special education program
    - d. improve conditions in a specific state institution
    - e. improve quality of any service for handicapped children



- You can boycott: 1. your child's school
  - 2. your child's state institution
  - 3. any facility whose services you are dissatisfied with

A boycott can be a limited one and involve only handicapped children and their parents. But an universal boycott involving non-handicapped children and their parents as well (to open a special classroom in a public school that has none, for example) would be ideal.

#### STEPS TO FOLLOW

- Follow steps outlined for registration drive and march.
- 2. Get at least 50% of the parents committed before you go shead with plans for a boycott. A successful boycott must have at least 50% participation. The more participation, the more successful your boycott will be. A boycott that has 100% participation or close to it will usually reach its objective.
- 3. Substitute another activity, (similar in nature to the activity you are boycotting). Examples:
  - a. A "model school", manned by ex-teachers, if you are boycotting a school.
  - b. A "model home", manned by social workers, psychologists, and other professionals, if you are boycotting a state institution.

The "model school" can be held in someone's home, in a church, youth center, or other facility. It can also be held in the lobby of the Board of Education (see "Organizing a Teach-In" in this chapter).

The "model home" can be in someone's home, a church, youth center, or other facility. It can also be in the lobby of the agency responsible for the bad conditions you are protesting (see "Organizing a Camp-In" in this chapter).

4. Have a list of demands to present to the agency



you are boycotting. Decide ahead of time those demands which MUST be met and those which you are willing to forego until a later time.

- 5. Give the agency you are boycotting two weeks to meet your demands before you put your boycott into effect (remember if you give the bureaucracy more time it will simply take the extra time and still not get the job done).
- 6. Don't call off your boycott until all your MUST demands are met.
- 7. Make sure you have adequate press coverage before and during your boycott. Follow steps outlined in Chapter IX, "How To Make Headlines".

## ORGANIZING A TEACH-IN

A teach-in, as defined in this manual, is a public teaching of handicapped children excluded from public school. The ideal place for the Teach-In is the lobby of the Board of Education Building, where volunteer special education teachers are to conduct classes for handicapped children who have been refused public school placements.

## Purpose:

To dramatize the lack of educational facilities for handicapped children and to pressure the School Board into opening new facilities. The teach-in tells the public that many handicapped children are not being educated, and, therefore, a special education classroom will be held in the lobby of the Board of Education Building until these children are properly placed.

# STEPS TO FOLLOW

- 1. Follow steps outlined in organizing a registration drive and organizing a march.
- Get a solid commitment from at least 20 parents (you can expect about 10 to show up) to participate in your Teach-In.



- 3. Get a solid committment from at least 3 teachers to participate.
- 4. Get at least one lawyer committed to take care of any legal problems that might come up.
- 5. Make an all-out effort in your publicity campaign (see Chapter IX, "How To Make Headlines"). Whether or not you get your objective depends largely on what kind of publicity you get. If your teach-in gets good press coverage on television, radio, in the newspapers you should get new classrooms in short order.

## ORGANIZING A CAMP-IN

A camp-in as defined in this manual is the camping-in, in City Hall, of a number of families whose children are victims, or potential victims, of lead poisoning, a major cause of mental retardation in the inner city.

## Purpose:

- \*To dramatize the danger of lead poisoning and the negligence of landlords and city officials responsible for proper code enforcement.
- \*To put pressure on city officials to provide strict enforcement of the building code.
- \*To prevent lead poisoning and mental retardation caused by lead poisoning.

# STEPS TO FOLLOW

- Contact your local building department and community organizations and get a list of buildings in your community that have been reported for violations which might lead to lead poisoning.
   Ex. peeling paint, plaster, etc...
- Get a copy of the building code from city hall, building department, your community organization, alderman, precinct captain.



- 4. Contact families of victims and potential victims and ask them to help you organize a camp-in.
- 5. Canvass your neighborhood, going from door to door, for building violations and ask residents to participate in your camp-in. Give them a flyer announcing the event.
- 6. Follow steps outlined in "Organizing a Registration Drive", "Organizing a March', "Organizing a Teach— In".
- 7. Make a massive effort to get good publicity. The success of your camp-in depends on it. See Chapter IX, "How To Make Headlines".
- 8. Be prepared to spend several days weeks if you can. Come prepared with all necessary equipment sleeping bags, blankets, camp stoves, ice boxes, pots and pans, food, furniture.
- 9. Bring all the children their toys, tricycles, etc... Let them behave as if they were home, letting them play, make noise, sing, etc...
- 10. Use the City Hall Lobby as you would your own home.

# ORGANIZING A PUBLIC HEARING

Many public agencies - such as the Board of Education - have annual public hearings for citizens and organizations to express their views.

These hearings provide an unique opportunity for parents and professionals. A fantastic impact can be made if a large number of parent and professional groups turn out, each demanding more facilities for handicapped children.

The impact can be so great that it can literally change the priorities of your Board of Education, your Mental Health Department, your State Legislature, Congress, and other bureaucracies. It can also give headlines in all the newspapers.



Such a miracle actually happened in Chicago, in the 1969 hearings of the Board of Education budget. The Council mobilized 23 organizations who each presented a statement demanding more educational facilities for handicapped children.

This made such an impact on the Board of Education that the budget was changed, and the special education appropriation was increased by one-third, making it possible to serve an additional 10,000 children than the Board had planned to serve. (The following year the Board doubled its special education budget before the hearings.)

Your parent group can do the same. If you mobilize all the parent and professional groups in your community to make presentations at your public hearings - you, too, can change priorities.

#### STEPS TO FOLLOW

- Find out all specifics from your local Board of Education (or other public agency).
- Write a letter (make it a personal letter if you can) to all parent and professional organizations in your area, informing them of the hearings and their special significance. Tell them it is imperative that they participate and why.

SAMPLE LETTER:

Dear		
On	your organization has ar	unique
opportunity to tell	the Board of Education h	low to
spend taxpayers' mom	ney.	

On that day, all organizations providing services to children are invited to participate in public hearings, setting priorities in education.

We believe the education of handicapped children must be a top priority when this year's budget is drawn up. If you feel the same way, please let the Board of Education know.



Last year's budget appropriated \$ for the education of handicapped children, far too little to serve all the children that need services.

This year's Eudget will be no better unless we tell the Board en masse, that SPECIAL EDUCATION MUST BE A TOP PRIORITY.

Won't you	join (	us	on		at	the	Board	of
Education				(	addı	ess)	2	

WE CAN CHANGE THE BOARD OF EDUCATION'S PRIORITIES. IT'S IN OUR HANDS.

#### Signature

- 3. Be sure you include in your letter any procedures that may be required for organizations to participate (such as a letter of notification to the sponsoring agency), deadlines, etc...
- 4. Bring buttons, armbands, etc... to identify the organizations as united in their demands.
- 5. Bring extra copies of your group's statement to pass around to members of the press and others attending the hearing. Urge other groups to do the same.

# ORGANIZING YOUR OWN PUBLIC HEARING

If your local School Board has no public hearing, organize one of your own.

# STEPS TO FOLLOW

- Decide on a central issue for the hearing or several specific issues.
  - a. lack of facilities
  - b. poor facilities
  - c. lack of funds
  - d. lack of teachers and other personnel
  - e. other lacking services
- 2. Ask key Board members to serve as panelists.



3. Make up a list of questions to ask panelists at the hearings. Also encourage questions from the audience.

e.

- 4. Follow Steps outlined in Chapter II, "Organizing a Parent Group" Section, "Organizing a Public Meeting".
- Appoint or ask for volunteers to take minutes of the hearings. Keep a record of all suggestions, complaints, etc...
- 6. At the end of the hearings, summarize issues of the hearing complaints, proposals for action, etc...
- Announce follow-up meeting to take action on complaints and proposals.
- 8. Ask for volunteers to draw up a report of the meeting to be presented to panelists and other appropriate authorities during special visit. Report should include proposed plan of action.
- 9. During visit to Board officials, give a deadline when you expect proposal to be implemented.
- Have an action plan ready in case your proposal is rejected.
- 11. Send the proposal and action plan to all press media, and invite them to attend special visit with Board officials.

# PICKETING

To get the most our of your picketing, choose your location and time carefully. Picket where the greatest number of people will see you at a time to coincide with a prominent event.

 Picket at a major airport at a time when the bureaucrat you are picketing is receiving an important dignitary. Ex. If you are picketing the Governor, choose a time when the President is coming to town (or another important official)



whom the Governor will obviously be greeting. Your message will then reach, not only the Governor, but the President and other important dignitaries assembled. Also the press and hundreds of people who turn out to see the President. Picketing at the airport, in front of the President and other dignitaries, will be very embarrassing to the Governor. His constituents already know how bad he is. Now, the whole world will know. And he'll find it hard to explain - to the President, other V.I.P.'s, foreigners, etc... why he is cutting services to handicapped children.

- Picket the homes, not the offices of bureaucrats. Everyone in the state capital knows how bad the Governor is. Everyone in City Hall knows how bad the Mayor is. But do the Governor's neighbors? The Mayor's neighbors? Your state representative's neighbors? Bring your message to their homes, their neighborhoods.
- Also picket those places where a specific problem exists which you want resolved.
- Follow steps outlined in "Organizing a March" and "Organizing a Rally".
- 5. Make sure your picketing is well covered by the press. Follow Steps outlined in Chapter IX.

#### CHAPTER VII

#### HOW TO MOVE BUREAUCRACIES

There are public servants who are sincerely devoted to handicapped children, who are making a major effort on their behalf - and who find themselves continuously frustrated by the bureaucracy employing them. Some of these have made a major contribution to the work of the Council.

But there are many more who simply fall in with the bureaucracy's slow motion ways, its rigid adherence to the status quo, its resistance to new ideas, new ways of doing things. How many children get hurt in the process



doesn't seem to concern them. These are the bureaucrats we are speaking of in this chapter.

To move bureaucracies you must constantly bear in mind that bureaucrats are public servants; that they are paid by you to provide services for you and your child; that you are the master, they are servants - not the other way around.

Parents who keep this in mind - and act accordingly - usually get action.

Parents who let themselves be intimidated and assume the role of servant to the bureaucrat's role of master usually wind up being treated like a servant. They often end up feeling guilty for having "bothered" the bureaucrat with their problems, for having taken up his valuable time, for having caused him work, etc.

You must remember that this is exactly what the bureaucrat is being paid for - and that you are paying his salary.

# TO MOVE A BUREAUCRACY:

- 1. You must stop feeling guilty and insignificant.
- You must stop apologizing for asking a bureaucrat to do a job you are paying him to do through your taxes.
- 3. You must stop begging for what you are entitled to by law.
- 4. You must not be patient. No matter how often you are told to please be patient, "we are doing everything we can", remember that patience has never moved a bureaucracy. Only impatience has ever made a bureaucracy move.
- 5. You must not accept those old excuses: "There isn't any money"; "We need more time"; "We've made a lot of progress"; etc...
  - a. There is never going to be any money unless



you demand it. What your tax dollars are spent for depends what taxpayers demand, how loudly and persistently they demand it.

- b. Be miserly with the time you give a bureaucracy to get a job done. It is a natural law of bureaucracies that the more time you give them, the more time they will take and often still not get the job done.
- c. If there is still a single handicapped child left unserved, the "progress" is not good enough. If more than half are unserved, there has been no progress - your district is barely standing still.
- shouting. Your voice will be lost in someone else's uproar. You can win battles, no matter how small your parent group, if you make enough noise. Remember, that's how Gideon won the battle of Jericho.
- 7. You must not be atraid to offend bureaucrats when:
  - a. they refuse to provide educational services which your child is entitled to by law.
  - b. they refuse to find a proper placement for your child in a state or private facility.

Do not be afraid to complain: to their superiors, your legislators, the mayor, your alderman, the governor, the newspaper, radio, television, and other press media. Do not be afraid to expose incompetence, inefficiency, dishonesty, stealing, bribery, or any other wrongdoings, no matter how powerful the guilty one.

Your child's welfare should be your primary motivating force, not the welfare of bureaucrats.

8. You must get rid of the attitude that "You can't fight City Hall", "Nothing Can be Done", etc... You must believe there is a good chance your problem will be resolved if you are persistent enough and determined enough to see the problem through.



9. You must use mass action. Remember that politicians are dependent on your vote and those of other parents, that all government officials are dependent on public support. This is why organized groups who make noise are so effective.

#### IT'S IMPORTANT TO:

- Determine whether the service you want for your child is a service you are <u>legally</u> entitled to or morally entitled to.
  - a. If it is a service you are legally entitled to, your best approach is the legal approach and your best argument is the law-and-order argument. Simply insist that the bureaucrat has no choice: he must obey the law and provide the service. As a bureaucrat, he cannot refute the law and order argument.

He cannot tell you that he does not intend to obey the law and not provide the service. He will demand more time (which you must not give him - give him a deadline instead). Continue to persist in your demands until you get the service.

b. If the service you are asking is one which is not required by state or federal law, but which your child, nevertheless, needs, use the strategies described in Chapter IV, "Making Your Parent Group an Action Group". Also take the necessary steps to get a law passed so that the service will be legally required. (See Chapter VIII, "How to Lobby and Get Results".)

# STEPS TO FOLLOW

- 1. Try to handle the problem at the local level first, through the bureaucrat who is responsible for the service.
- Write & letter to the bureaucrat, stating that your child is entitled to the service by law (if a service you are legally entitled to), that



every day your child does not receive this service he is in violation of the law, that unless the service is provided within two weeks (or give another deadline), you will take legal action.

#### SAMPLE LETTER

<b>5</b>	•
Dear	

My child is entitled to a public school education under (give the name of the law). Every day he is not in school you and other Board of Education officials are in violation of the law.

I must insist that you comply with the law, and that you provide a proper placement for my child within two weeks, or I will be forced to take legal action.

- c.c. (all persons listed below in No. 5)
- 3. Have the letter xeroxed, with at least 15 copies.
- If there is no reply within two weeks, call the bureaucrat and ask why there has been no action.
- 5. If you do not receive a satisfactory response, send the xeroxed copies of the letter to the following people:
  - a. the bureaucrat's superiors
  - b. the city director of the department
  - c. the county directory
  - d. the state director
  - e. your alderman
  - f. your ward committeeman
  - g. your precinct captain
  - h. your mayor
  - i. your governor
  - j. your parent group
  - k. your legislators, congressmen
- With each copy include a brief note, asking for help.
- At the same time that you are sending out your copies, have your parent group send out a letter



to the bureaucrat, demanding action on the problem Get other parents to write similar letters.

- 8. If you do not get satisfactory results, write to your local newspaper, to the Letters to the Editor section, explaining the problem and lack of action
- 9. Send a copy of your Letter to the Editor to the bureaucrat.
- 10. If your local paper has an "Action Line", write to them and send a copy of your letter to the bureaucrat.
- 11. If you local radio station has an "Action Line", call them.
- 12. Document evidence to show other parents are having the same problem (you can run an ad in your local paper, with your phone no. to get this information also a Letter to the Editor, with your phone no.) and ask the local paper to do an expose.
- 13. Send a copy of the letter asking for an expose to the bureaucrat.
- 14. If all the above have not brought satisfactory results, contact your local legal aid clinic (a federally funded clinic through the OEO would be your best bet), your local American Civil Liberties Union, and ask them to take your case to file a suit (they will usually do this at no cost to you). Or ask them to file a Class Action Suit.
- 15. Hire a lawyer to do just two things:
  - a. Write a letter to the bureaucrat (as your legal representative) stating that he is in violation of the law and that you will file a suit.
  - b. Phone the bureaucrat telling him the client is ready to file a suit unless the service is provided <u>immediately</u>.



It is doubtful that you will have to go through with legal action. Your child will probably receive the service somewhere between step #1 and step #15. But you must be prepared to take that recourse if you have to in order to get what you are after.

# NEGOTIATING WITH BUREAUCRACIES

A successful negotiator is one who is able to get more of his demands than the other side of the negotiating table. To be successful in negotiating with bureaucracies:

- 1. Do not be intimidated, either by threats, flattery, or friendliness.
- Do not let yourself be buried under a pile of excuses. Insist that the bureaucrats stick to the issue.
- 3. Be prepared with all the proper documents, evidence, etc... to support your demands.
- 4. If you are negotiating with bureaucratic lawyers, be sure you have a lawyer as a spokesman for your group. (You can probably get a volunteer lawyer from your parent group or local legal aid clinic.) He will be able to cut through unnecessary legal jargon and legal maneuvers and get the negotiations moving.
- 5. Insist that the bureaucrats keep a proper distinction between <a href="Legal">Legal</a> requirements and <a href="policy">policy</a> requirements. If the bureaucrats refuse a demand on grounds that "it would be illegal", demand to know the statute. Have a lawyer check the statute before you accept a claim that one of your demands is against the law. A demand is often turned down on the basis of legal requirement, when it is simply a policy requirement. A policy can be changed much more easily than the law (it can be done at the next meeting of the bureaucracy's board).
- If negotiations get bogged down, ask higher-ups to intervene. Write them letters telling them



why your demands are imperative. Present evidence and documentation. Then follow with a phone call, making a personal plea for their intervention. If they refuse, take the matter still higher up. Deluge them with letters, telegrams, and phone calls.

\*The Council successfully used the above techniques when negotiating a new contract with the Chicago Board of Education for special schools through its affiliate, the Administrators Private Care Association. Many schools felt the Board's contract did not protect them, that it would continue to cause problems in collecting tuition payments. Although a large number of the schools had already signed the Board's contract, a new contract drawn by the APCA's volunteer lawyer was eventually adopted.

- 7. Don't let the bureaucrats pass the buck from one department to the next. Insist beforehand on a clear line of responsibility, set down in writing. Make the bureaucrats stick to it.
- 8. If the bureaucrats still insist on passing the buck, assigning responsibility, blame, etc... to other departments, insist that higher-ups intervene to settle the issue, and get all the buck-passers together at the same meeting.
- 9. Never settle for less than 100% of your demands. But don't turn down 20% or 30% or even less.
  Just don't settle for it. Keep up the pressure until you get the full 100%.

# BUREAUCRATS - FRIENDS OR FOES?

If a bureaucrat gives you what you are entitled to, he is your friend. If he doesn't, he is your enemy.

It doesn't matter how friendly, how nice a bureaucrat is, if he does not give you the services your handicapped child is entitled to, he is not your friend.

Many bureaucrats use friendliness and flattery as a form of intimidation, another way to keep parents quiet while they go about their do-nothing routine.

Many parents fall for the "sweetness and light" routine. They believe that the way to get concessions from bureaucrats is to have friendly relationships with them. But when there is a friendly relationship, it's the bureaucrats who end up with most of the concessions.

Bureaucrats have all kinds of excuses why they cannot provide a service and do the job they are paid to do. If you are their friend, how can you not sympathize? How can you not understand? How can you not respond to their pleas and give them more time? Meanwhile you are sacrificing your child's welfare and letting him do without services he needs - because of your friendly relationship with bureaucrats.

Parents who succumb to friendly relationships with bureaucrats, with its give and take, will find that they wind up doing all the giving and the bureaucrats all the taking.

Some parents (usually officers in a parent group) derive ego-satisfaction from their friendly relationship with bureaucratic officials. While it is a necessary function of a parent group to maintain a cordial relationship with bureaucrats, the purpose of the relationship is to improve services for handicapped children.

Watch out for officers and staff members who use their position as a stepping stone to a bureaucratic post.

If an officer is afraid to insist on services because it may jeopardize his relationship with bureaucratic officials or future career, his relationship is detrimental to the group, and he should be replaced if your parent group is to remain effective.

Parents should not be afraid of getting a bad reputation with bureaucrats. A bad reputation usually means your group is effective.

When bureaucrats say nice things about a parent group - not only to their face, but behind their backs as well - that's the time to worry.



#### CHAPTER VIII

#### HOW TO LOBBY AND GET RESULTS

Many things that happen in your state legislature and in Congress affect you and your handicapped child. To have an effective parent group, you must be involved in lobbying. You must lobby in order to:

#### 1. be informed about:

- a. legislation which would help your handicapped child and must be supported.
- b. legislation which would hurt your handicapped child and must be defeated.
- 2. initiate legislation to benefit handicapped children - to provide services which are needed but not yet provided by law.

#### WAYS TO KEEP INFORMED

- Subscribe to legislative newsletters (your local Welfare Council, League of Women's Voters, Local Association for the Retarded, Crippled Children, Autistic Children, Children with Learning Disabilities, Blind, and Cerebral Palsy, will probably have one), which gives current reports on bills in your state legislature and in Congress.
- 2. Get copies of the bills that concern handicapped children (from the same sources of #1 above or from the sponsor of the bills).
- 3. Decide which bills your group supports and wage a massive campaign to get them adopted.
- 4. Decide which bills your group opposes and wage a massive campaign to get them defeated.
- Decide what legislation you would like adopted which has not yet been introduced and wage a massive campaign to get it introduced and passed.



- 6. Have each of your parents make a personal visit, accompanied by others in the district, to their legislators and congressmen to:
  - a. urge them to support or oppose legislation according to your group's position.
  - b. urge them to introduce new legislation.

#### THE CAMPAIGN

- Mimeograph or otherwise reproduce a list of all the state legislators and congressmen in your area, with their home and business address, home and business phone numbers.
- 2. Pass it out or mail it to all your members.
- 3. Set up a legislation committee, headed by a legislation chairman or co-chairmen. Her (their) responsibility will be to appoint and keep in close touch with "key members" in each area - an area to be composed of approximately five districts (the number of districts will vary, depending on the area covered by your parent group).

# Duties of Key Members

- Inform members in their districts of the status of all pending legislation your group is supporting and opposing.
- 2. Urge them to write, phone, or wire depending on the time and urgency involved - their representatives, urging them to vote for or against the legislation.
- 3. Have members report back to "key members" the response of their representatives (this will let the "key member" know if the job has been done and how the representatives are responding).

# CRUCIAL TIMES WHEN PARENTS MUST CONTACT THEIR REPRESENTATIVES:

1. When a bill is in committee.



- 2. When a bill is before the House.
- 3. When a bill is before the Senate.
- 4. When a bill has been passed and is ready for the Governor's or President's signature.
- 5. When one house does not concur with an amendment offered by the other house, and the bill is sent to a Conference Committee (which is composed of appointed members of both houses).

When a bill which your group supports or opposes is in any of the above stages, it is time to set your legislative machinery rolling and get your parent group in action.

Your legislation chairman should keep in close touch with "key members" during each stage so she can assess the chances of the legislation passing or not, and whether or not the campaign needs to be stepped up.

# SPECIAL STRATEGIES TO PUSH A BILL THROUGH OR GET IT DEFEATED

- 1. Call a legislative press conference of all legislators in your area and ask them to make a public commitment for (if a bill your support) or against (if a bill you oppose).
  - a. Get <u>all</u> your members to call their representatives to assure their attendance at the press conference.
  - b. Have your members keep a record of the positions of their representatives.
  - c. After the press conference, send out a press release to all press media (see Chapter XIV, "How To Make Headlines"), all representatives and everyone on your mailing list, listing the positions of all the representatives. Urge your members to send thank-you notes to those favoring your group's position, and a letter urging them to change if opposed to your group's position.



\*The Council used the Press Conference Strategy when severe cuts were made in the state mental health budget in 1970. The Council joined a coalition of many groups to fight the cuts. For the first time in Illinois history, 2/3 of the cuts were subsequently restored.

- 2. Organize bus loads and car loads of parents to attend public hearings of crucial bills in your state legislature and Congress.
- 3. Appoint a representative from your group to present a statement at the hearings, outlining the reasons why your group supports or opposes the bill. Urge other parent groups to do the same.
- 4. Picket the homes of legislators and congressmen (on week-ends when they are usually home) who refuse to support or oppose bills you consider crucial.
- 5. Organize a legislative tour of state institutions (follow steps outlined in #1 above for legislative press conference).

# AFTER THE LEGISLATIVE SESSION IS OVER

- 1. Inform your members how their representatives voted on bills your group supported or opposed (your local public library, League of Women Voters, etc... should have this information).
- 2. Urge them to write thank-you's to those who supported your position and express their disappointment to those who took the opposite position.

Remember that your legislator's primary concern is to remain in office. Your campaign must be conducted with this thought constantly in mind. You must somehow convey to your legislators that supporting your position will help them remain in office and non-support might mean their defeat.



#### CHAPTER IX

#### HOW TO MAKE HEADLINES

Publicity - the art of making headlines - plays an important role in making your parent group effective. It plays a crucial role in the success of any action you undertake to move bureaucracies.

The kind of publicity you get will determine how much you are able to extract from bureaucracies out of your demonstrations, sit-ins, teach-ins, camp-ins, etc...

The publicity you get from one event can also help assure the success of another. Parents who have read about your sit-in in the newspapers or seen it on television, will be more willing to participate in your group's next activity.

Bureaucracies will be more responsive to your demands if your group's activities have received wide coverage. They will be more likely to acquiesce to your demands - at the mere threat of a demonstration, sit-in, etc. - in order to avoid bad publicity.

#### WHY PUBLICITY?

- 1. To establish an identity for your group in the public's eye.
- 2. To focus public attention on the critical need for better facilities for handicapped children.
- 3. To inform parents what their handicapped child is entitled to under the law and how they can obtain these benefits.
- 4. To enlarge your group's membership.
- 5. To publicize activities of your group.
  - a. special meetings
  - b. sit-ins
  - c. demonstrations
  - d. rallies and marches



- e. press conferences
- f. teach-ins
- g. camp-ins
- h. workshops
- i. benefits
- j. all other activities that need publicity
- 6. To move bureaucracies.

#### HOW

- 1. Through press releases of all major activities sent to:
  - a. all local newspapers to the attention of (find out their names):
    - 1. City Editor
    - 2. Education Editor
    - 3. Feature Editor
    - 4. Political Editor
    - 5. Chief Editorial Writer
    - 6. Health Editor
    - 7. appropriate columnists
    - 8. all reporters who have written articles about handicapped children and related areas
    - 9. to the photo desks of all major newspapers
  - all community newspapers to the attention of Editor.
  - c. all radio and television stations to the attention of:
    - 1. News Desk Editor
    - 2. Community Relations Director
    - all radio and television people who have given time to activities concerning handicapped children and related areas.

# WRITING A PRESS RELEASE

1. Use your organization letterhead, if you have any. If not, make sure the name, address, and phone

number of the organization is at the top.

- 2. On the right side, just below the letterhead, put the name and phone number of at least two people who can be reached during the day, to answer questions about the events you are publicizing.
- 3. Your release should be double spaced and should answer the following questions:
  - a. Who?
  - b. What?
  - c. Where?
    d. When?
  - e. Why?

Your release can take the above form if you like, with the WHO, WHAT, WHERE, WHEN, WHY, in bold letters, each starting a new paragraph.

- 4. Use a snappy opening which will at the same time give all important facts listed in #3:
  - a. Name the organization sponsoring the event.
  - b. What kind of event.
  - c. Where it will be held.
  - d. When it will be held.
  - s. Why it is being held.
- 5. After the WHY come specific details:
  - a. Speakers and their affiliations.
  - All additional information.
- 6. The above sequence is reversed if the speaker himself is more newsworthy than the event: Ex. if the Governor or Mayor is the speaker.

# SAMPLE PRESS RELEASE

CO-ORDINATING COUNCIL FOR HANDICAPPED CHILDREN 407 S. Dearborn Room 1090 Chicago, Illinois 60605

For information call:

Mrs. Charlotte Des Jardins 684-5983



#### **NEWS RELEASE**

# CRISIS IN HB 2671 TUITION REIMBURSEMENTS FOR HANDICAPPED CHILDREN

Because of a crisis in HB 2571, tuition reimbursements for handicapped children who must attend special schools, parents and their children will hold a <u>sit-in</u> at the Chicago Board of Education, 228 N. LaSalle, on Wednesday, February 25, 11 a.m.

HB 2671 provides tuition reimbursement to special schools for children too severely handicapped for public school special classrooms.

Not a single special school has received reimbursement for any Chicago children since they were first due five months ago. Several schools are facing a financial crisis as a result.

State officials have announced no applications will be approved after March 1, for the current school year.

47 special schools and several thousand children in Chicago alone are affected by the crisis.

Parents will not leave the sit-in until authorized representatives from their special schools have collected reimbursement for every eligible child.



The <u>Sit-In</u> is sponsored by the Co-Ordinating Council for Handicapped Children, a coalition of parent and professional organizations.

#### WHEN PRESS RELEASES ARE USED

- 1. Approximately 10 days before the event, the first release should be sent.
- Three or four days before the event, a second release should be sent.
- 3. If only one release can be sent, it should be sent 4 days before the event. Sending two releases instead of one emphasizes the importance of the event, and gives your release more chance of being printed.
- 4. Call the morning of the event at 9 a.m.:
  - a. all city editors of major newspapers.
  - b. all news desk editors of television stations.

This is to confirm that reporters and photographers and cameramen will cover the event. This is crucial for demonstrations, sit-ins, etc. It is not so important for meetings unless they are of special significance.

#### AT THE EVENT

- 1. Have a prepared statement about the WHY of the event, and what you hope to accomplish by it, to give to the press.
- 2. Have a brief information piece about your organization to give to the press.
- 3. Have flyers explaining the WHY of the event to hand out to the public.



 Designate someone from your group to act as spokesman to the press (the head of your group, or chairman of the event).

#### AFTER THE EVENT

- 1. Write thank-you notes to all reporters who covered the event in the newspapers, radio, television. (This is important to keep the good will of reporters and keep them interested in your organization.)
- Thank-you notes should be written within a week after the publicity has appeared.

# ORGANIZING A PRESS CONFERENCE

Follow all steps outlined above pertaining to press releases.

# HOW TO GET FEATURE STORIES

One of the best ways to publicize an event is to get the press to write feature stories about the problem which the event is focusing on. Ex., If your parent group is having a Teach-In to focus public attention on the lack of educational facilities for handicapped children, feature articles documenting the lack of facilities should provide great publicity.

\*When the Council had a public rally in September, 1969, Illinois' new Mandatory Special Education Law was coming into effect the day school opened. The Council knew the law was not being implemented, that few handicapped children would be going to school. That's why the Council was having a rally.

Nevertheless, to get advanced publicity for the rally, the Council asked all four major Chicago newspapers to write feature stories on a handicapped child's "First Day in School". All four papers thought it was a good idea. And they proceeded to call member organizations of the Council for information. Out of approximately a dozen groups called, they discovered that not a single handicapped child (who was not previously attending school)



was going to school for the first time that September. All of the parents were still waiting for word telling them where their children were supposed to go.

It was clear that the new mandatory law was not being implemented. Instead of feature stories on "A Handicapped Child's First Day in School", the headlines read "90,000 Kids Out of Luck" (from Chicago Today), "Schools Unable to Obey State Law" (from Chicago Sun-Times), "Special Education Has Slow but Steady Progress" (from Chicago Tribune).

# TO GET A FEATURE STORY:

- Write a letter to all city editors of major newspapers, suggesting a specific angle, or giving specific details which would interest the editor in an expose. Make sure the name and phone number of at least two people appear on the letter.
- 2. Call approximately 5 days after you amiled the letter, asking if he is interested in your suggestion. Provide a little more information in your phone call (information which will get him interested), but keep it brief, less than 5 minutes.

SAMPLE LETTER (This is the letter that resulted in 4 feature stories as described in above paragraph.)

Dear	

September 3 is supposed to be the first day of school for thousands of handicapped children. For on that day, the Mandatory Special Education Act is supposed to be in effect. And handicapped children in the state of Illinois are at last supposed to get the education they are entitled to.

But thousands of handicapped children in Chicago still have not been placed. What is holding up the action?

Is it lack of money? The Legislature appropriated more than \$36,000,000 for special education, for the four remaining months of 1969. What is the Chicago Board of Education doing with its share of this money?



Is it lack of trained teachers? A community resources inventory conducted by Step, Inc. and the Child Care Council revealed more than 25 professional agencies offered to help train teachers on a volunteer basis for the Board of Education. Why hasn't the Board ever accepted this offer?

Each year your newspaper does an article on "The First Day in School". We believe an article on "A Handicapped Child's First Day in School" would be particularly appropriate at this time. Thousands of parents and professionals in the Chicago area would be particularly interested.

Signed Phone

#### OTHER PUBLICITY PLACES

- 1. Newspaper columnists on:
  - a. Education
  - b. Mental Health
  - c. Politics
  - d. Medicine
- Letters to the editors.
- 3. "Action Line" or similar columns which provide service to readers.

# FLYERS AND POSTERS

Flyers and posters should be used to publicize every major activity. They should be on colored paper, with art work if possible (done by a volunteer artist), or an attractive, eye-catching layout.

The following information should be on posters and flyers:

- 1. The event (in BOLD LETTERS), in a prominent place.
- Date, time, and place (also BOLD LETTERS, but slightly less bold than the event, also in a prominent place).
- 3. Reason why event is being held if reason is crucial to the event.

- 4. Name of sponsoring group.
- 5. Names and phone numbers of at least two persons who can be called for additional information.

#### HOW MANY?

300 posters and 3,000 flyers will cover approximately all stores, all schools, public and private agencies of a community of 50,000. There will be approximately 1,000 flyers left to hand out in shopping centers the Saturday before the event.

#### PRICE

- Approximately \$5-\$10 per thousand (\$15-\$30 for 3,000) flyers printed offset.
- Approximately \$3 per thousand (for paper alone) for mimeographing (\$9 for 3,000).
- 3. Approximately \$10-\$20 for 300 posters printed offset.

# SPEAKERS

Another way to get publicity for your group is to send speakers out to other organizations. Send a letter to all groups that have a concern for handicapped children - all professional and parent groups, PTA's, Kiwanis Clubs, Lion Clubs, Rotary Clubs, Shriners, Moose Lodges, Businessmen Association, etc. - telling them you have speakers available. Suggest a topic. Include a return form and return evelope for their reply. Follow up with a phone call.

You'll not only get good publicity, you'll probably get money, too.

# WIRE SERVICES

All major newspapers subscribe to national wire services which report news on a national and international basis. They are:



- Associated Press (the newspapers' own wire services).
- United Press (a private wire service).
- 3. Reuters (a British-owned wire service).
- 4. Your local News Bureau (if yours is a large city).

For events of major importance, where there is a possibility of national and international coverage, send your release to all the above wire services. Examples:

- 1. A legislative press conference in which many congressmen are expected to participate.
- 2. A national or international personality who is appearing at a major event.
- 3. A national or international convention.
- 4. An activity in which thousands are expected to participate.

#### NEWS BUREAU

If your parent group is short on trained volunteers - and you are located in a major city - you should consider subscribing to your local News Bureau.

For a small fee the News Bureau will send your release through its wire service to all metropolitan newspapers in your city, all radio and television stations. For an additional fee, it will send the release nationwide.

Cost: Annual membership: \$25-\$50 + cost per release: \$15-\$40

Cost of City News Bureau in Chicago:

\$50 annual membership

+ \$15 per release (members) \$25 per release (non-members)

# IT'S IMPORTANT TO:

1. Have good timing. Have your press conference etc... immediately after a crisis has been reported - the same day or the next. It's too



late to have it a week or a month later. It's no longer NEWS. Have a special policy for emergency cases so that your leaders can call a press conference on short notice - without going through a Board of Directors meeting.

- 2. Always tell the truth. If you lie or exaggerate you will be found out sooner or later. The word will get around and your parent group will lose out on publicity.
- Know reporters by name, their field of interest, previous articles written, etc... Look over your newspapers for names of reporters who write articles on mental health, education, health, and children. Send them releases of all major activities. Write and ask them to do features. Follow up with phone calls.
- 4. Respond to articles and programs about handicapped children.
  - a. If the article is about a major crisis, such as cutbacks in special education or mental health services, immediately call a press conference to protest the cuts.
  - b. Write a letter in praise of an article or program that supports your group's position.

#### Write to:

- 1. The City Editor
- 2. The reporter who wrote the article
- 3. The Letters to the Editor Section
- 5. Pick a good time and location for activities.
  - a. Time: Morning is best so that activity will be covered in both morning and afternoon papers. Weekdays are best, because newspapers have full force working.
  - b. <u>Place</u>: The best location is downtown near the newspaper offices. If you have no downtown office for a press conference, ask a hotel for the use of a room. Many



hotels are willing to let groups use their rooms free of charge for press conferences.

# Special Places:

- 1. The lobby of the Board of Education or outside the building is the ideal place for a press conference protesting cuts in special education. Ideal time is an hour before the Board's regular meeting.
- 2. The lobby of the State Building, or outside, where the Department of Mental Health has its headquarters, is an ideal place for a press conference to protest cuts in mental health.
- 3. The lobby of the state capitol, or outside, is ideal for a press conference protesting (or urging) passage of a crucial bill.
- 6. Keep trying. Don't give up if your activities don't get coverage the first few times you try. Keep sending releases and letters suggesting different angles. Keep in touch with reporters. Vary your approach in releases and letters. Many groups who are making headlines today seldom got a mention in the press when they first started out.
- 7. Remember that ACTION MAKES NEWS. The more action, the more headlines your group will make.

#### CHAPTER X

#### THE POWER OF SPEECH

Silence is not golden for a parent group. Silence only begets a lot of nothings for parents of handicapped children - nothing in legislation, nothing in services, nothing in funds for programs, nothing in publicity, and nothing in power.

In order to get parent power, a parent group must be



vocal. It must be vocal about the needs of handicapped children and make demands for improved services. It must be vocal through the press, through the state legislature, through public hearings of their School Board, their Mental Health Department, and other bureaucracies. (See Chapter VI, "How To Make Your Parent Group an Action Group".)

It must be vocal by sending speakers to a variety of organizations, participating in radio and television talk shows, conference and workshop panels.

Vocalizing needs and demands is necessary for your parent group to accomplish the following:

- 1. Promote your parent group and increase membership.
- 2. Make the public aware of the critical need for services for handicapped children.
- 3. Make the state legislature aware of the need for services, and enlist their support for better legislation.
- 4. Make bureaucracies aware of your parent power and make them grant your demands.

# PROVIDING SPEAKERS FOR OTHER ORGANIZATIONS. STEPS TO FOLLOW:

- 1. Send a letter to all groups that have a concern for handicapped children, telling them you have speakers available.
  - a. Other parent groups
  - b. Professional groups
  - c. PTA's
  - d. Kiwanis Clubs
  - e. Lion Clubs
  - f. Rotary Clubs
  - q. Shriners
  - h. Moose Lodges
  - i. Businessmen's Association
- Suggest a topic.



- 3. Include a return form and return envelope for a reply.
- 4. Follow-up with a phone call.

SAMPLE LETTER
Dear
IF YOUR WOULD LIKE TO KNOW MORE ABOUT THE CO-ORDINA- TING COUNCIL FOR HANDICAPPED CHILDREN AND ITS WORK
IF YOU WOULD LIKE THE COUNCIL TO HELP YOU ORGANIZE A PARENT GROUP OR ANOTHER ORGANIZATION TO HELP HANDI-CAPPED CHILDREN
IF YOU WOULD LIKE THE COUNCIL TO HELP YOUR ORGANIZATION GET BETTER SERVICES FOR HANDICAPPED CHILDREN
IF YOUR ORGANIZATION WOULD LIKE TO JOIN AND BECOME ACTIVE IN THE COUNCIL
THE CO-ORDINATING COUNCIL FOR HANDICAPPED CHILDREN WILL BE HAPPY TO SEND A GUEST SPEAKER AT NO FEE TO TALK TO YOUR ORGANIZATION. SIMPLY FILL OUT THE FORM BELOW.
(tear on dotted line)
NAME OF YOUR ORGANIZATION
ADDRESS
CITYSTATEZIP
OFFICER TO CONTACT PHONE
DATE AND TIME: (if known)
TO BE ARRANGED
DO YOU HAVE A SUBJECT PREFERENCE?
MAIL TO: (Name of your organization)

# RADIO AND TELEVISION TALK SHOWS

Every radio and television station has a number of talk shows where issues of general interest are aired. These

(Address of your organization)



present an unusual opportunity for your parent group to tell the public about:

- Your organization, its goals, accomplishments, and special projects.
- A special event such as demonstrations, sit-ins, etc.
- 3. A crisis for which you are mobilizing parents such as mental health budget cuts, special education cuts, etc.

#### TO GET ON THE SHOW

- Follow steps in "How to Get a Feature Story", Chapter IX.
- Suggest specific people, and the contribution they can make to the program.
- 3. Give reasons why the issue which you wish aired is particularly timely at the moment.

# PARTICIPATING ON CONFERENCE AND WORKSHOP PANELS

After you have sent speakers to a number of meetings, participated in a number of radio and television talk shows, made headlines through a variety of activities - your parent group will be asked to participate in conference and workshop panels.

In providing speakers for workshops and conferences, radio and television talk shows, organization meetings, etc... you should make sure that the speaker will be an effective one and will make a good representative of your parent group.

# HOW TO SELECT EFFECTIVE SPEAKERS

An effective speaker is one who:

 Can capture the attention of the audience and invite a positive response.



- Can speak extemporaneously, with a minimum of notes, and does not have to rely on a written, prepared speech.
- 3. Is fully prepared with statistics and available information at her fingertips - to respond intelligently to questions.
- 4. Can appear relaxed and comfortable while speaking.
- 5. Is sincere.
- 6. Presents a positive image of your parent group.

It is not necessary for a parent to be a trained (or even an experienced) public speaker to be an effective one. Parents who show an interest and ability in speaking should be encouraged to fill speaking engagements - starting with small groups and graduating to larger groups and panel.

Although the head of your parent group will naturally be asked to fill most speaking engagements, other qualified officers and members should be encouraged to fill speaking engagements whenever possible.

It's important to appoint only those members who are good speakers - and not fall into the trap of "honoring" hardworking, devoted members who have no speaking ability and who are uncomfortable in public speaking. This is unfair to both the organization who has requested a speaker and to your own parent group as well.

Remember that the speaker you send is representing your parent group. If she does a good job it will earn a big plus and give your group more parent power. But if she does a poor job, it will reflect poorly on your organization and will earn it a big minus in the eyes of the sponsoring group.



#### CHAPTER XI

#### HOW TO OPEN A CLASSROOM IN THE PURLIC SCHOOLS

If your handicapped child has been placed on a waiting list for public school placement, you should try to get a special classroom opened for him and others in a public school somewhere in your district.

If you state has mandatory special education legislation (as Illinois has) you can use the legal angle and serve notice to school officials that they must obey the law and open a classroom for your child.

If you state does not have mandatory legislation, you should try to get such a law passed (see Chapter VIII, "How To Lobby and Get Results").

You can also use the 14th Amendment to the U. S. Constitution, the equal protection of the law clause, to claim a public school education for your handicapped child as a right specifically granted by the Constitution to all children. This was successfully done in October, 1971, by the Penn. Association for Retarded Children in a class action suit against 13 Pennsylvania school districts. You can also appeal on moral grounds, that your handicapped child cannot be denied any of the benefits granted to other children.

You should also do the following:

 Place an ad in your local paper, asking for the parents of children with the same handicap as your child, and the same age bracket (within 3 years) to contact you to open a public school special education classroom. Make sure you include your name and phone number.

# SAMPLE AD

Parents	of		ch	ildren	(your ch	ild's
handicap	) with	ages			, please call	
			number)	to hel	p open a	
special	educati	ion cla	assroom	in loca	l public	school.

Signed
Your name and phone number



- Write a letter to the editor telling why a special education classroom is needed, asking for the help of parents. Sign your name and phone number.
- 3. Set up a meeting with the parents who respond to the ad and letter.
- 4. Determine what kind of classroom you want.
- Get the help of teachers, social workers, psychologists, and other professionals to help you determine what kind of classroom your children need.
- 6. Make a survey as a group of local public schools (simply call the schools, or ask friends and acquaintances who might know) to determine what schools in your district have empty class-rooms.
- 7. If there is no classroom space in your district, look for space that could be rented to the Board of Education in churches, youth centers, settlement houses, hotels, other public and private places.
- 8. Make an appointment with the principals of the schools with empty classrooms to discuss the possibility of using them for special education.
- 9. If your state has mandatory legislation, appeal to the principal on legal grounds. If your state does not have mandatory legislation, appeal to him on moral grounds. In any event, ask him to request that the empty classrooms be used for special education, that one classroom be specifically used for the children of the parents in the group. (If you have at least 5 parents, your chances of getting a classroom are good.)
- 10. If the principal refuses and your state has mandatory legislation - notify him in writing through a registered letter signed by all the parents, that you will take legal action.



- 11. Follow up your letter with a phone call, asking "when" not "if" you can expect the classroom to be opened.
- 12. Follow steps outlined in Chapter VII, "How To Move Bureaucracies".

#### CHAPTER XII

HOW TO OPEN YOUR OWN SCHOOL AND GET FUNDING FOR IT

If your child's handicap is such that he needs a private school placement - and there is none available - you should consider opening your own school.

It may sound like an impossible task. But many parents have done it - parents with no experience whatsoever, but a lot of determination, and a willingness to work hard to make their dream come true.

You can do it too.

#### STEPS TO FOLLOW

- 1. Follow the steps in the previous chapter.
  "How To Open a Classroom in the Public Schools".
- 2. Advertise for professionals as well as parents to help you open your school.
- 3. Set up a professional advisory committee made up of professionals who are willing to help. Their duties will include:
  - a. Advertising for staff for your school through local papers, professional magazines and newsletters, etc.
  - Interviewing applicants and making arrangements for hiring.
  - c. Explore the possibility of obtaining donated services from private and public agencies.



- 4. Set up a Citizens Advisory Committee made up of people who can help you raise funds. Their duties will include:
  - a. Soliciting businesses for funds for your school.
  - b. Soliciting wealthy individuals.
  - c. Soliciting foundations.
  - d. Sponsoring fund-raising affairs.
- 5. Look for space free space preferably.
  - a. In churches.
  - b. In public housing projects.
  - c. In youth centers.
  - d. In private and public schools.
  - e. In private and public agencies.
  - f. In homes which can be converted.
  - g. In apartment buildings.
- 6. Apply for State Charter and Tax Exemption (see Chapter III, "The Nuts and Bolts of Your Parent Group").
- 7. Apply for funding for your school.
  - a. To the Department of Mental Health.
  - b. To foundations (get a list from your local library. Ask other organizations for a list.).
- 8. Your proposal for funding should include the following information:
  - a. What your program consists of.
  - b. What kind of children it will serve.
  - c. What kind of staff you will hire.
  - d. What the purpose of the program is.
  - e. What mades the program unique and different from other programs.



- f. Information about your Board of Directors.
- g. Information about your professional advisory committee.
- h. Information about your citizens advisory committee.
- i. Your budget for the next year.
- Anticipated income (including sources other than the grant you are applying for).
- k. Information about your state charter (do you have one, did you apply for one?).
- Information about your tax-exempt status. (Are you a tax exempt organization? Did you apply for tax exemption?)

Include a cover letter with your proposal, addressed to the attention of the Executive Director of the foundation (find out his name).

Have a title page, on top of the proposal itself, with the name of your organization, address, phone, and the name, address, and phone of an officer.

Bind your proposal in an inexpensive folder.

If you have not received a reply within 6 weeks, call the director and ask if the proposal has been received, when you may expect a reply, etc.

# IT'S IMPORTANT TO:

- 1. Have a school that does not discriminate on the basis of race, religion, or economic group.
- Have a school that operates democratically, with shared responsibilities between parents and staff.
- 3. Have good communication between parents and staff.
- 4. Place emphasis on services to the children not on fancy classrooms, offices, highly paid administrative staff (you don't want another bureaucracy).



5. Start small and expand as you go along. Many schools start with less than a dozen children.

#### CHAPTER XIII

#### THE ROLE OF THE PROFESSIONAL

If your parent group is an effective one, many professionals (psychologists, psychiatrist, teachers, social workers, etc.) will want to join and become active.

Many professionals genuinely want change, having become more and more frustrated by bureaucracies, trying to place children in non-existent facilities or in very poor public facilities.

Professionals can make a major contribution to your parent group. Their expertise, their wide range of knowledge and experience, their special skills, their professional connections can be a major asset.

Two of the Council's major accomplishments - "Your Guide to Services for Handicapped Children" and "Your Rights as Parents of a Handicapped Child" - were done largely by professionals who volunteered countless hours to these projects.

But there can be drawbacks in involving a large number of non-parents in a parent group, and parents should be aware of them in order to keep their group effective:

- 1. The major hazard is in the make-up of your group.

  If the majority of members of your parent group
  are non-parents, you no longer have a parent group.
- 2. The next hazard is in the direction your group can take if the majority of members are non-parents and therefore not directly involved in the problems which precipitated the formation of the group. The direction will tend to be towards less action, more talk.
- 3. Professionals may be reluctant to act because their jobs may be in jeopardy.



4. A large professional membership may frighten away parents who may feel uncomfortable, uninformed, etc., in the presence of a preponderance of professionals.

### WAYS TO AVOID HAZARDS

- Keep the majority of board positions and officers in the hands of parents.
- Encourage the professionals who are "doers" to become officers and policy makers. Keep the "nondoers" in an advisory capacity.
- 3. Encourage parents to assume more responsibility in policy making, in chairing projects (see Chapter V, "Uncovering Buried Talent"). Have professionals working under their supervision instead of always the other way around.
- 4. Set up a Professional Advisory Committee. Give them a free hand on projects. Suggest to them some of the projects in Chapter VI, "How To Make Your Parent Group an Action Group".
- 5. Encourage parents and professionals to learn from each other.

### HOW TO ATTRACT PROFESSIONALS

If your parent group's problem has been lack of professional involvement, follow these steps:

- Contact professional organizations in your area - first by letter, then by phone, telling them about your organization, asking for their participation.
- 2. Contact private and public agencies.
- 3. Contact special schools, hospitals, camps, etc.
- 4. Flace an ad and write a letter to the editor to your local paper.



- 5. Invite them to your next meeting. Have a list of projects, committees, etc., you'd like them to work on. Ask for their ideas, to add to your prepared list. Make specific assignments on projects they would like to volunteer for.
- 6. Follow up on assignments. Have them report at meetings. Keep them involved.
- 7. Involve professionals in ways that utilize their special skills:
  - In setting standards for schools, clinics, treatment centers, etc.
  - b. In drawing up plans for new facilities.
  - c. In recruiting talent for new facilities.
- 8. Appeal to professionals as citizens, with a special responsibility to handicapped children. Ask them to make a commitment to get better services.

### CHAPTER XIV

#### THE STUDENT'S ROLE

If your parent group has been making headlines, college students in your area (perhaps even high school students) will want to become involved in some of your projects.

Students can contribute much to a parent group and their participation should be encouraged.

### STUDENTS CAN:

- Bring new ideas, new vitality, new ways of doing old things to a parent group.
- 2. Serve as volunteers in special schools, state institutions, camps, etc. They can work with handicapped children, take them on field trips, and provide a meaningful relationship on a one-to-one basis which the children may never have otherwise.



- Serve as baby sitters, "big brothers", "big sisters", to handicapped children, taking them on outings, etc.
- 4. Initiate projects in which parents can participate and vice-versa.
- 5. Use their special skills and know-how on a variety of research projects: in state institutions, public schools, special schools, etc.
- Provide manpower to demonstrations, marches, sit-ins, etc.
- 7. Participate in public hearings.
- 8. Help in distributing and mailing flyers, posters, etc.

\*College students made a major contribution in the Council's fight against a \$31 million cut in the 1970 mental health budget. They proposed a legislative press conference where the state's leading democrats would make a public committment against the cuts. Council members improved on the idea and decided that a bi-partisan press conference involving state legislators from both parties, from as many districts as possible, would be even better.

Within one week, students and parents had called 67 of Chicago's 82 state representatives and senators to invite them to the press conference. Twenty-five promised to come. Fifteen actually showed up to make their public commitment.

The press conference was covered by Chicago's five major channels and four major newspapers, and dozens of community newspapers.

After the Press Conference, an announcement showing where the 67 stood on the cuts was sent to all press media, all state legislators, and the Council's 2000 mailing list. Students and parents were urged to write thank-you notes to legislators who opposed the cuts and to urge the uncommitted (only one was willing to commit himself as for outs) to vote against the cuts.

Meetings were subsequently held with the acting director of the Illinois Mental Health Department. A coalition was formed. Hundreds demonstrated in the state capitol and other public places. Dozens of organizations testified against the cuts at public meetings of the state legislature.

The outcome: 2/3 of the cuts were restored.

### HOW TO ATTRACT STUDENTS

- Contact your local colleges and universities.
   Tell them about your parent group and some of its activities. Ask how you can involve interested students.
- Put notices of all your meetings and activities on college and university bulletin boards (include a name and phone number whom interested students can call).
- 3. Send press releases of your activities to all college and university publications in your area. Ask for student volunteers, and include phone numbers where they can call for more information.
- 4. Set up a special student auxiliary. Give them a free hand on projects.

#### CHAPTER XV

#### THE ROLE OF VOLUNTEERS

If you have an active parent group - particularly if your activities receive wide press coverage - your parent group will be contacted by a variety of people who wish to be involved as volunteers.

Some will have special skills or talents; publicists, artists, photographers, writers, organizers, fund raisers, etc. Or they may have some time which they would like to contribute doing some of the many chores that organizations must do to stay alive and well: addressing and stuffing envelopes, typing, mimeographing, driving and pick up service, etc...

(The Council's booklet covers, its stationery, and some of its posters were designed by a professional photographer and artist who volunteered their services to the Council.)

Don't turn away anyone who volunteers to do anything. Immediately do the following:

- Take their name, address, phone number, and general area of interest.
- 2. Invite them to your next meeting.
- 3. Ask them what project they would like to work on and turn their name over to the appropriate chairman.
- 4. Follow up to make sure the chairman has given them an appropriate assignment.

### HOW TO ATTRACT VOLUNTEERS

- Place an ad in your local newspaper, asking for volunteers for specific jobs.
- Put flyers and posters in shopping centers, stores, churches, etc., asking for volunteers for specific jobs.
  - 3. Send a press release to your local papers, radio and TV, telling them what your group does and its needs for volunteers.

### SAMPLE AD

HRLP WANTED: NO PAY! Only the satisfaction of doing a job that is really needed, a job that will help provide better services for handicapped children. Jobs available (list them). For more information call (list at least two phone numbers of people available during the day).

# KEEPING VOLUNTEERS

It's usually harder to keep a volunteer than to get one.

Often a woman will be spurred to volunteer by an article

she has read in the papers, exposing bad conditions in state institutions, lack of services, etc. She wants to help. She wants to do everything she can.

But after she commits herself, she sometimes becomes bored, tired, involved in other activities, and finds it hard to keep her commitment on a continuing basis.

If the volunteer feels her efforts are really worthwhile, if she feels her work is really essential, she will not get bored or tired very easily, and she will discontinue other activities to concentrate all her time in the job. she will constantly find new energy to do her work and will be happy doing so.

### MOTIVATING VOLUNTEERS

- Show your volunteers that you really appreciate the job they are doing. Don't take their work for granted.
- 2. Take advantage of every opportunity to honor your volunteers. Send in the names of your most devoted volunteers to the "Volunteer of the Year" award. Send their names to newspapers, radio and television stations, in connection with the award, telling them why they deserve to win the award.
- Include a volunteer on radio, television, and newspaper interviews whenever it can be done appropriately.
- Always include the name and address of the chairman in a news release publicizing an event.
- 5. Assign your volunteers projects they really want to work on. Don't give them only drudge work.
- 6. Ask your volunteers for ideas on new projects and ideas on how to improve old ones.



#### CHAPTER XVI

#### THE ROLE OF THE HANDICAPPED ADULT

Children grow up. Your handicapped child will grow up and take his place in the adult world. What kind of a world will it be?

This will depend on the groundwork you and other parents have laid in his childhood years: on the education and training you have provided him; on the preparation you have made for his adult years.

Among the people most qualified to help you plan your child's future are handicapped adults. They can also be a great help in problems you may have with your chill. They can give you a perspective on what your child is feeling and experiencing.

It's not too early to start now during your child's early years to assure a better future for your child: better employment and housing opportunities, better workshops, better facilities all around, and all benefits granted to other Americans.

You can help safeguard your child's future by becoming active in organizations for handicapped adults, supporting their campaigns for better legislation, better housing, better employment opportunities, better financial and medical assistance.

Helping handicapped adults get better jobs will mean a better job for your child when he grows up. Helping handicapped adults get better housing will mean a better home for him when he's on his own. Helping handicapped adults get more financial assistance, better medical care will mean more financial assistance and better medical care for your child when he needs it.

Joining campaigns for minimum wage laws and other benefits will mean securing those benefits for your child.

Invite members of organizations for handicapped adults to your meetings and ask their help and support for your



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campaigns. Attend their meetings and offer your help and support for their campaigns. Establish liasons with their organizations, exchange newsletters and other information material.

### Set up a special committee to:

- 1. Improve state institutions and nursing homes.
- 2. Get ramps on buses and public places.
- 3. Establish job agencies for the handicapped.
- 4. Get transportation for the handicapped.
- 5. Get better medical care and public aid.

Remember how long it takes to move bureaucracies -- usually years. It's not too early to start now to safequard your child's future.

#### CHAPTER XVII

#### HOW TO ORGANIZE A COALITION

When your parent group is well established, when it has successfully engaged in a number of activities, you will begin to see the advantages of joining with other groups to form a coalition.

### ADVANTAGES OF A COALITION

- 1. You can present a united front to bureaucracies and get better results. By reaucracies will not be able to play one group against another if you are united in your demands, and make your demands on behalf of all handicapped children not just retarded children, blind children, etc.
- You can present a united front to legislators and get better legislation. Instead of legislation only for retarded children, only for blind children, etc... it can be time for all handicapped children.



- 3. You can provide better services for children and parents in your group if you co-ordinate your activities with other groups.
- 4. You can increase your power, multiplied by the number of groups in your coalition.

A coalition can be made up of only parent groups or it can include professional groups as well.

### STEPS TO FOLLOW

- Send a letter inviting prospective embers to an organizing meeting. Mention all the advantages members can gain by belonging to a coalition. Follow up with a phone call.
- 2. Follow steps outlined in Chapter III, "The Nuts and Bolts of Your Parent Group".
- 3. Make up a list of prospective members.
- 4. Send prospective members an invitation letter stating:
  - a. The advantages of joining the coalition.
  - b. What the coalition expects to accomplish.
  - c. Duties and responsibilities of members.
  - d. Annual dues of members.
- 5. Enclose a copy of Goals Statement and By-Laws with the invitation letter.
- 6. Enclose membership form and self-addressed return envelope.
- 7. Follow up the letter by a phone call from a group committed to the coalition. Ask to meet with the group to discuss possible membership.
- 8. When the coalition has at least 10 organizations solidly committed, call a press conference to announce the formation of the Coalition.
- Send out announcements to all bureaucracies,
   state legislators, and congressmen.

- 10. Decide on a list of projects for the coming year. Make assignments and follow through.
- 11. Follow steps outlined in Chapter III, "The Nuts and Bolts of Your Parent Group".

#### CHAPTER XVIII

### YOU CAN DO IT WITHOUT MONEY--ALMOST!

By now you are probably saying, "We'd like to do all this. But we just don't have the money."

Most of the suggestions in this booklet can be carried out with no money - or practically no money. Many of the activities and projects can pay for themselves.

Don't be deterred from undertaking a project just because your group has no money. Use the ACTION NOW--PAY LATER plan. Charge everything and pay as the money comes in.

Try to make your projects pay for themselves. Take up a collection at public meetings to pay for the cost. If you decide to publish a Directory of Services or other publications, charge for the cost.

### WAYS TO KEEP EXPENSES DOWN

- Use equipment (mimeo machine, xerox machine, adding machine, electric typewriters) of your community groups, churches, public and private agencies instead of buying your own.
- 2. Buy your mimeo paper, envelopes, stationery, stencils, and other supplies in quantity, whole-sale. Find out from other organizations where they get theirs and compare prices. Also use the yellow pages of your phone book and call suppliers for price quotations.
- 3. When you have material printed, use offset instead of having type set up by the printer. Offset is a photographic process which comes much cheaper than setting type. But your material must be



camera ready. It will come out exactly the way you give it to the printer. Therefore, all typewritten material should be done with an electric typewriter; all illustrations should be carefully done; spacing and layout should be good.

- Hve printed and mimeographing material in large enough quantities to last at least six months.
- 5. Get a non-profit bulk mailing rate. Cost will be approximately a of regular mail. Get details from your local post office.
- 6. Send all printed material 4th class (but do not enclose any personal letters). This is a of regular mail.
- 7. Get a call pack for the major officer in your group who makes the most phone calls. Call your local telephone service for details.
- 8. Pass the hat at public meetings to cover the cost of the meeting.
- 9. If you serve refreshments, have members take turns in bringing them instead of taking out the cost from the central kitty.
- 10. Get as much of your work done by volunteers as possible: typing, filing, art work, publicity, newsletters, pictures, all clerical work.

Most organizations use annual or semi-annual fund raisers to meet expenses. Following are five popular fund-raisers which parent groups and other organizations have used most successfully.

### FIVE POPULAR FUND-RAISERS

### Movie Benefit

 Get a catalog of old movies from a distributing agent in your area (consult the yellow pages of your telephone book).



- Pick a movie that would appeal especially to children, but which the whole family would enjoy as well. Try to pick one that hasn't been shown on television recently.
- 3. Select a free showing place (or one you can use for a nominal fee) from churches, youth centers, private and public agencies in your area.
  - a. Make sure the room holds at least 200 people preferably 300.
  - b. Try the accoustics to make sure sound will come out all right.
  - c. Find out if the agency loaning you the space has a screen. If not, make arrangements to rent one (consult the yellow pages of your phone book).
- 4. Date: Pick a school holiday (when mothers are looking for special activities for their children) or a Sunday afternoon.
- 5. Time: Have several showings one in the morning, and two in the afternoon. (10 a.m., 1 p.m., 3 p.m.)
- 6. <u>Price</u>: Charge 24% to 40% less than your local movie theater. 50¢ to 75¢ for children; \$1 to \$1.25 for adults.
- 7. Publicity: Follow steps outlined in Chapter IX, "How To Make Headlines" (section on flyers and posters).
- 8. Tickets: Give every member at least 10 tickets to sell. Also give others who have indicated an interest in your group at least 10 tickets. Keep track of the number of tickets sold on a weekly basis. Give more tickets to those who are doing well. Urge slackers to get going.

# Play Benefit

- Set up a committee made up of the following persons:
  - a. General chairman

- b. Sponsor chairman
- c. Ticket chairman
- d. Publicity chairman

# 2. The Committee together will:

- a. Select a play.
- b. Select a date (allow at least 2 months).
- c. Compose a letter and design a flyer to send to everyone on the mailing list. Letter should briefly tell about your parent group, why it needs money, what it proposes to do with the money raised.

# 3. Duties of the General Chairman:

- a. Co-ordinate activities of sponsor chairman, ticket chairman, and publicity chairman.
- b. Co-ordinate general mailing: getting enough people to address, stuff, and mail envelopes. Mailing should include letter, flyer with tear off sheet for ticket orders, self-addressed return envelope, and a brochure about your parent group, if you have one. It should be mailed 4 to 6 weeks prior to the benefit date.
- c. Appoint ticket-sellers and ushers for the night of the benefit.

# 4. Duties of the Sponsor Chairman:

- a. Make up a list of potential sponsors and patrons who will give \$10 and \$25 respectively for the benefit (they will receive 2 tickets). Use lists used by other organizations in their benefits. Include the businessmen and professionals in your area, and anyone who might give \$10 or \$25 to your organization. This is a good time to approach people you have been meaning to ask for money but never got around to.
- b. Make up a list of potential "angels", people who might give \$100 or more. Also include businessmen and professionals on this list.



- c. Use basic letter used for general mailing, making appropriate changes.
- d. Send letter, flyer with tear-off sheet, brochure and return envelope to sponsor and angel list. Mailing should go out 4 to 6 weeks prior to the benefit date.
- e. Follow up mailing with phone call to potential sponsors and patrons who have not replied within 10 days.

### 5. Duties of the Ticket Chairman

- a. Distribute at least 10 tickets to members and other interested persons.
- b. Check weekly with ticket holders. Give more tickets to those who are doing well. Try to motivate slackers into selling more.
- c. Fill ticket orders coming in from sponsor mailing and general mailing. Include a thank-you letter. Make sure sponsor tickets are reserved, with choice seats.

### 6. Duties of the Publicity Chairman

- a. Follow steps outlined in Chapter IX, "How To Make Headlines".
- b. Put posters in all stores, shopping centers, etc.
- c. Prepare a display about your organization to be displayed in the lobby or at the door.

# Raffle

- 1. Decide what you want to raffle: a trip, television set, radio, etc.
- 2. Try to get the merchandise donated. Write a letter to several companies that sell the merchandise, tell them about your organization, why you need money, etc... and ask them to donate the item for your raffle.



- 3. Follow up each letter with a phone call.
- 4. Give each member at least one book with 20 chances each (or two books with 10 chances each) to sell.
- 5. Check with sellers at least once a week.
- 6. Announce winners at a major event (annual meeting, etc.).
- 7. Publicize winners, sending out news releases to appropriate newspapers.

# Cocktail Party

- Select a prestigious home or apartment for the party.
- 2. Arrange to have all liquor donated. Contact liquor stores in your area by letter, telling them about your organization and why it needs money. Follow up the letter with a personal visit and ask for liquor and soft drinks.
- Arrange to have all food donated. Ask members to bring hors d'oeuvres, potato chips, nuts, pretzuls, cookies, etc.
- Arrange to have napkins, glasses, cups, coffee, donated by members.
- Follow steps outlined for Play Benefit. Sponsors are not necessary, but you may have them if you wish.

# Pot Luck Supper

- Follow steps outlined for Play Benefit (no sponsors).
- Indicate on flyer that people are to bring a dish: meat, fish, salad, dessert, rolls and butter, etc... You can assign certain dishes by



alphabetical listing (A-E bring meat dish, E-H bring salad, etc...).

### OTHER WAYS TO RAISE MONEY

- Set up a Women's Auxiliary (or a Men's Auxiliary), whose specific job will be to raise funds for your group.
- Contact wealthy individuals who might be willing to contribute at least \$100 to your group (first by letter, followed by a personal visit).
- 3. Have annual membership drives.

#### CHAPTER XIX

#### HOW TO KEEP YOUR PARENT GROUP FROM DEATH'S DOOR

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

A parent 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 gradually wanes until the group finds itself at death's door.

The death of a parent 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 group cannot act in a crisis. Your parent 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 group cannot prevent a crisis. But a live one can. Crises usually happen when no one is watching. A parent group serves as a continual reminder to bureaucracies that someone is watching and they will react accordingly. A 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 group can quickly reverse the tide once a crisis had hit and minimize its effects.

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

# WAYS TO KEEP YOUR PARENT GROUP ALIVE AND WELL

- 1. Get a new focus, new problems to tackle to replace the one which was the springboard for your group. You won't have to look long. There are plenty of problems in your community, your city, your state (see Chapter VI, "Making Your Parent Group an Action Group").
- 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 handicapped children. No money is needed for this, except an initial investment to cover the cost of the first printing. Figure out all costs (costs of printing, mailing, etc...) and charge double. You will probably wind up just breaking even. (The Council undertook such a project the first year of life. It was compiled entirely by volunteers, most of them professionals. Two thousand were sold the first year.)
  - 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, etc. (Another project undertaken by the Council. Ten thousand copies were sold in two years.)

- c. A parent-helper program, whereby one parent is assigned to help another who needs help moving bureaucracies. See Chapter VII, "How To Move Bureaucracies" (The Council has such a program and is thus able to help parents on a one-to-one basis.)
- 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 group well oiled and ready for action in a crisis. Regular meetings enable you to keep your membership informed on issues, and prepared for action whenever necessary.
- 4. Have an Open Door Policy. Welcome anyone interested in your group's efforts rich or poor; white, black, 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 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 have you got to hide?).
- Have an active membership committee, continually seeking new members (see Chapter III, "The Nuts and Bolts of Your Parent Group").
- 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.)

- 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. (See Chapter IX, "How To Make Headlines".)
- 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 group's time should be spent on moving bureaucracies 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 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 gripe. 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 group is to improve services for handicapped children, not to provide ego satisfaction to members. There is nothing wrong with deriving ego satisfaction out of the work done for the parent 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 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 for the welfare of all handicapped 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:
  - a. Monthly newsletters.
  - b. Reports of all activities.
  - c. Monthly treasurer's reports.

#### BY-LAWS

# CO-ORDINATING COUNCIL FOR HANDICAPPED CHILDREN

#### ARTICLE I

Name

The name of this organization shall be The Co-Ordinating Council for Handicapped Children.

#### ARTICLE II

### Purpose

The purpose of this organization shall be to obtain better services for all handicapped children.

#### ARTICLE III

# Section A Individual and Family Members

Any individual or family who subscribes to the goals of the Co-Ordinating Council for Handi-capped Children may become a member. Individual and family memberships are contributing memberships only and do not entitle a member to voting privileges. Membership entitled an individual to al mailings, monthly newsletters, and meeting notices.

# Section B Organization Membership

Any organization that subscribes to the goals of the Co-Ordinating Council for Handicapped Children upon payment of annual dues becomes a member. Voting rights are limited to organizations only. Each organization may appoint one person to serve as a voting delegate.



#### ARTICLE IV

#### Section A

Officers will be elected annually at the September meeting.

#### Section B

The nominating committee composed of at least five members shall be appointed by the Board of Directors at the August meeting to nominate officers and committee chairmen. Nominations will be accepted from the floor at the September meeting.

### Section C.

The officers will be:

- 1. Co-Ordinator
- 2. North Side Co-Chairman
- 3. South Side Co-Chairman
- 4. Secretary
- 5. Treasurer

#### Section D

All organization members have one vote regardless of the size of the organization.

#### Section E

In the case of a tie vote; the Co-Ordinator will break the tie.

#### Section F Vacancies

The Co-Ordinator and the Co-Chairmen with the approval of the Board of Directors shall be empowered to fill any vacancies that may occur.

### Section G Removal of Officers

Officers may be removed for gross neglect of duty by majority vote of the Board of Directors.



### Section H Quorum

One-third of the Hoard of Directors constitutes a quorum.

### Section J Annual Report

The Co-Ordinator and Co-Chairmen shall submit an annual report to the State of Illinois in accord with The General Not-for-Profit Corporation Act: Section 63.

#### ARTICLE V

### Board of Directors

The Board of Directors of this organization shall consist of all voting members in good standing. They shall have the power to make all policy for the organization.

### ARTICLE VI

# Section A Regular Meetings

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

# Section B Special Meetings

Special meetings to discuss and take action on energencies shall be called by special arrangement of the officers. In the event of a crisis or other emergency situation where a meeting of the entire rembership is unfeasible, the officers shall be empowered to take proper action.

#### ARTICLE VII

The nominating committee shall appoint committee chairmen. However, the Co-Ordinator and the Co-Chairmen with the approval of the Board of Directors shall nave the power to set up new committees as @ ded.

#### ARTICLE VIII

Affiliation

The Co-Ordinating Council for Handicapped Children is a coalition of parent and professional organizations. Any organization, individual, or family subscribing to the goals of the Council may become affiliated through membership.

#### ANTICLE IN

Section A Individual Membership

The dues of the organization shall be \$5.00 per year payable in advance for individual or tamily memberships.

Rection B organizational Membership

organization Dues shall be \$25.00 per year.

#### ARTICLE X

Disbursement of Funds

The funds of this organization shall be deposited in a bank selected by the treasurer with the approval of the Co-Ordinator. The treasurer shall be bonded. All financial obligations of the organization shall be discharged by check on approval of the Co-Ordinator and signed by the treasurer and Co-Ordinator.

### ARTICLE MI

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

#### ARTICLE XII

Amendments



These By-Laws may be amended at any regular meeting of this organization by an affirmative

vote of two-thirds of the members present and voting provided the proposed amendment has been read to the general membership.

#### ARTICLE XIII

Dissolution

In the event of dissolution, all assets remaining after meeting all liabilities shall be distributed to one or more organizations for handicapped children selected by the Board of Directors.



# CO ORDINATING COUNCIL FOR PUNDICALTED CHILDREN

the Co-Ordinating Council for Handicapped Children is a coalition of parent and professional organizations concerned with the special needs of all handicapped children. It is composed entirely of volunteers.

The long range goal of the Council is to obtain better services for all handicapped children at the earliest cossible age. Immediate goals of the Council are: to obtain full and meaningful implementation of special education legislation; to provide means through which parent organizations can communicate with each other and nelp each other; to provide direct means through which parents can obtain services for their children from public and private agencies; to educate the public in the need for better services for all handicapped children.

# What can You bo to help the council reach its goals and Hill Your Child.

- Join and become active in a parent group, professional group, or citizens group whose goal is to obtain better services for all handicapped children.
- fersuade your group to join the Council if it is not already a member.
- 3. Organize a parent group, professional group, or citizens group - and have the group become a part of the Council.
- 4. Become an individual or family member of the Council. (You would get a monthly newsletter with upto-date news of new services, new legislation, Board of Education activities, etc...)
- 5. Contribute financial and moral support to further the work of the Council.
- 6. Refer parents you come in contact with to the Council and its participating and member organizations.

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### OTHER COUNCIL PUBLICATIONS

"YOUR RIGHTS AS PARENTS OF A HAMPICAPPED CHILD"

Explains provisions of the Mandatory Special Education Law (HB 1407) and the Tuition Reimbursement Law (HB 2671) and lists necessary steps parents must follow to obtain educational services as provided by law.

Available in English and Spanish.

Price: .50¢ per copy +/84 pestage.

"YOUR GUIDE TO SERVICES FOR HANDICAPPED CHILDREN"

A spiral bound, 220-page book with over 400 listings of Chicago area (including suburbs) for all categories of handicapped children.

# LISTINGS INCLUDE:

Private Schools
Camps
Mental Health Centers
Evaluation Centers
Clinics
Parent Groups
State Institutions
Private Agencies
Public Agencies

Price: \$1.50 per copy +184 protage

