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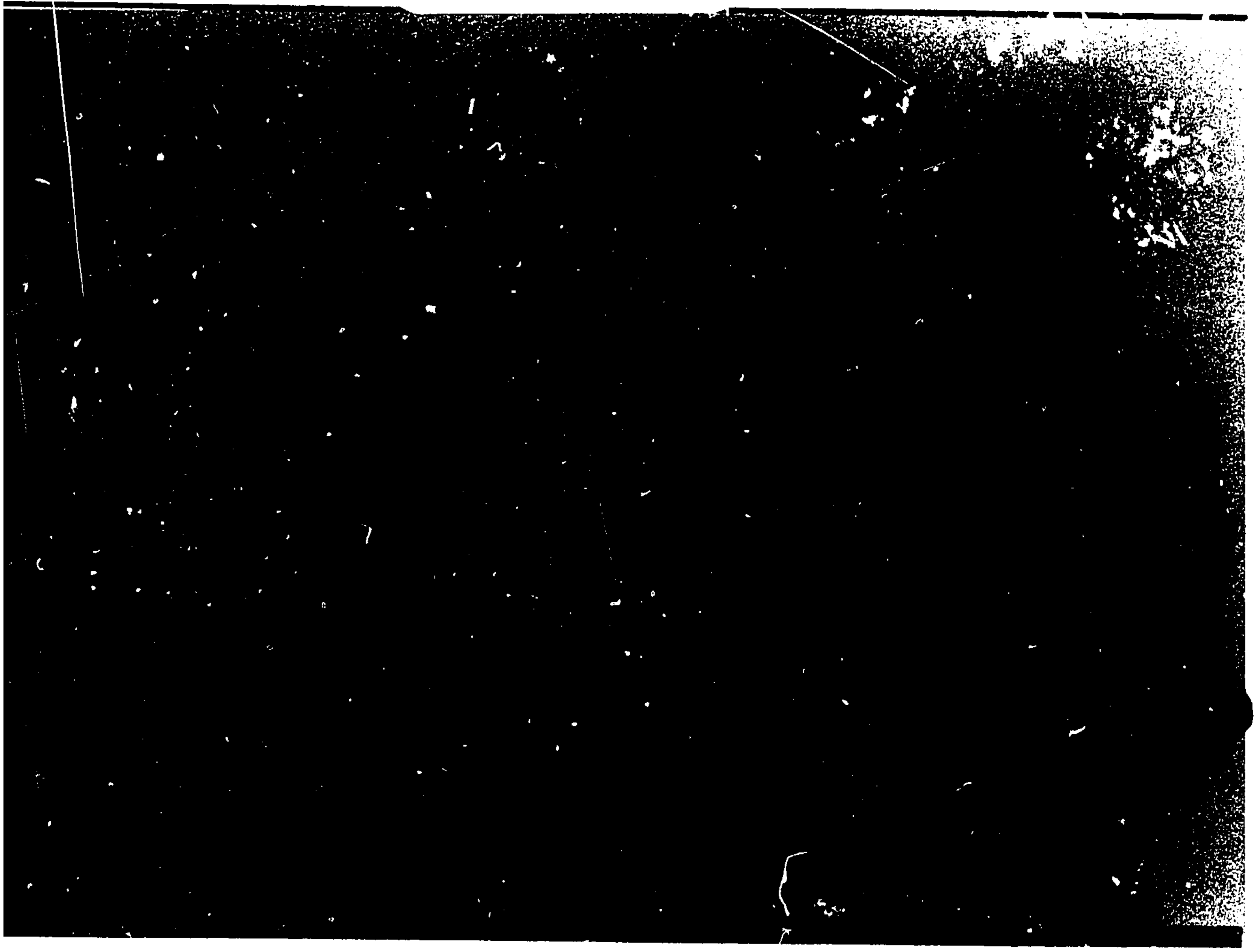
ABSTRACT

Third in a series of Project REACH (Regular Education for All Children with Handicaps) documents is a manual intended for parents of severely disabled students. The manual is centered on ways parents can work together to mobilize community support groups. Formation of a parent support group, the role of the parent facilitator, and ways to acquire and interpret needs assessment data are examined. The parent support group's function in information sharing and support and in advocacy-action is analyzed, as is the group's role as trainers for the community. Approaches to increase participation of community agencies are described, with emphasis on newsletter publication and community participation in parent group meetings. A brief discussion of formative and summative evaluation is followed by appended materials, including a list of resources for topical presentations and parent support. (CL)

Parents And Community Together

PACT



reach

PARENTS AND COMMUNITY TOGETHER

(P.A.C.T.)

by

Ann Tiedemann Halvorsen

Editor: Jane Margold

The P.A.C.T. was developed through the cooperative efforts of San Francisco State University and San Francisco Unified School District.

Wayne Sailor, Ph.D., Principal Investigator

Notice

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I. INTRODUCTION TO THE PARENT-COMMUNITY MANUAL

A. The Purpose of the Manual

This manual was written for the parents of severely disabled students. It is also for people interested in helping parents form support groups that will make it easier to deal with the home, school, and community issues that most affect children with disabilities. Because the manual describes in detail how to start a parent support group, and how to ensure that parents' information and training needs are being met, we anticipate that the book will also be useful to PTA's; to university personnel who train special educators; to school district community advisory councils; to community agencies serving severely disabled clients; and to teachers, social workers, and administrators.

During Project REACH, we found that one major problem facing parents was an overwhelming lack of information. In response to our needs assessment, the parents reported that they knew little about existing community services for severely disabled children. They weren't sure what their sons' and daughters' educational rights included, or what the goals of integration* are. These were some of the broad issues that were unfamiliar to parents; many also needed more information on appropriate curriculum, instructional techniques, and educational objectives. We realized that these gaps in the parents' knowledge hampered their ability to particpate in school and community decisions regarding their children. As a result, there were inequities in the distribution of services, since parents who were most aware of local resources generally obtained these services for their children; the others did not (Brewer and Kallikak, 1979). The latter then tended to depend too heavily on the school district for services outside the realm of the district's responsibility (e.g., after-school programming). At the same time, community agencies that could have been developing services were not being utilized. As one example, the community Parks and Recreation Department could have been including severely disabled children in its programs if parents had known how to advocate forthe integration of their children into park-sponsored activities. For these reasons, informational presentations were a primary focus of REACH parent support groups, and informational sessions always preceded action on specific issues.

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* Terms that are asterisked are defined in the **Glossary**.

In addition to information, parent groups that Project REACH worked with expressed a desire to learn advocacy/action strategies, and community outreach* and awareness training techniques. We also focused on techniques for mobilizing community agencies, networking, and recruiting new parents. Sections of the manual deal with these practices so that the reader can adopt or adapt them to match the needs of the parent population to be served.

B. Three Options for Involving Parents in the Education of Their Children: the Parent as Teacher Model, the Mixed Model, and the Trainer of Trainers Model

The techniques we suggest for meeting the information and training needs of parents come from three models that researchers have used to broaden parents' participation in the education of their disabled children: the parent as teacher model, the mixed model, and the trainer of trainers model.[1]

The first of these, the parent as teacher model, permits the least amount of parent involvement in the design of their child's program. Instead of planning out their own participation, parents are usually told by the classroom teacher how to continue the school program at home.

Generally, this model focuses on training the parent in operant techniques and related methods of behavior management. The parent also learns to implement classroom objectives and programs that include data collection at home (cf., Filler and Kasari, 1981). This type of parent involvement assumes that the child's classroom teacher is willing to make home visits to initiate and monitor the program, and that the parent is able to carry out some of the same functions as the classroom teacher, so that the child can apply new skills in several environments.

The parent as teacher model is one of several possible options in the mixed model (Bricker and Casuso, 1979). In this model, a person may be appointed by the parents as a parent group leader/facilitator.* The parent facilitator may then help parents gain access to community resources, provide parents with information about their legal rights, and act as a liaison between the parent and advocacy groups or social services. The facilitator may also help form parent support groups. This model assumes that parents have information and training needs that require attention either before or at the same time as they acquire the skills to act as teachers of their child at home or in the community.

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* See the Glossary

Of the three models, the trainer of trainers model (Jenkins, Stephens and Sternberg, 1980) requires the greatest degree of parental involvement. In this model, parents are recruited to serve as trainers of other parents who have similar interests and needs. This model reaches more parents and maximizes their efforts to a greater degree than the first two models, since parents receive training and information that enables them to function as effective advocates for their severely disabled child. These parents can then help other parents acquire similar skills and become more actively involved with their children's education. Ideally, the trainer of trainers model is sustained by continual recruitment of new parents, so that the program eventually becomes independent, and the parents don't have to rely on professionals within the school system for their activities and continued involvement. This model is based on several assumptions: that parents are interested in working on a volunteer basis with other parents, that their job schedules allow them to do so, and that the professionals within the school district can provide whatever initial training and information are necessary.

Those who serve a diverse group of parents will probably find, as the REACH staff did, that elements of all three models will be useful. Since the San Francisco schools that participated in the REACH project are not only multiethnic but are also multilingual, we found that a combination of all three models enabled us to provide information and training to parents whose familiarity with school district procedures, attitudes toward advocacy, and feelings of self-confidence differed greatly. To ensure that the parents' needs were being met, one key feature of our approach was to use a needs assessment. The other was to make sure that existing community agencies and services were as closely involved in our program as they could be.

C. Key Features of the Parent Program: Assessing Parents' Needs, and Linking Parents with Existing Services and Resources

As you probably realize, the knowledge level, skills, time constraints, work schedules, and previous experiences of parents of severely disabled students will vary greatly, and so will their interests and priorities, according to the age of their child, and the level at which the child functions. Although it may be perfectly obvious that a single uniform program of parent involvement won't meet the needs of all the parents of severely disabled students in a given classroom, this common-sense observation is frequently made, and then overlooked in parent programs (Turnbull & Turnbull, 1982). For this reason, Chapter 2 presents several ways of assessing parents' needs that have worked for Project REACH.

Another key point that this manual stresses is the need to create activities that are not simply duplications of existing services within the district or community. We wanted to ensure that our program wouldn't disappear as soon as federal funding had ended -- a possibility if community agencies hadn't become involved and demonstrated enough responsiveness to parental priorities to stimulate the parents', schools', and agencies' continued investment in the practices we were trying to establish.

To maximize the participation of existing community agencies in a parent program, we suggest a number of techniques and strategies (see Chapter 5) that proved to be effective in San Francisco. As one aspect of this effort to involve community agencies, we also recruited parents to serve on committees within agencies, such as: the San Francisco Community Advisory Council for Special Education, the Developmental Disabilities Area Board V, and the Special Education Resource Network. As a later section of the manual explains (see Chapter 4) the parent support group formed at each school site can serve as the focal point for outreach activities involving parents, thereby ensuring that the same outreach attempts aren't repeated unnecessarily by every organization.

There are several strong arguments for linking parents with community agencies. First, if the specific activities that the parents' support groups evolve become part of the role of a community organization, the parent program is more likely to continue. Equally important is the fact that many specialized community agencies that provide educational, recreational, and vocational services to people with severe disabiliites want greater participation by their clients' parents. Most of us who are either parents of severely disabled children, or professionals working with parents, have generally seen the same few faces at meetings of the local Association for Retarded Citizens (ARC), the special education advisory board, the school board, and similar organizations. Professionals working with parents, and the more active parents themselves, need to recruit "new blood" into these groups to maintain a balance between parents and professionals in agency decision-making processes, to improve parent-professional relationships, and to see that successful programs are maintained.

Other vital functions that parents can perform are to encourage, advocate for, and assist in the planning of new programs for severely disabled clients of school age and beyond. Often, service agencies lack programs that continue the efforts of schools to prepare students with severe disabilities for life in their communities. For example, in San Francisco, few of the adult vocational programs that currently exist are open to clients with severe disabilities. These clients may not meet current entry-level requirements, such as independent toileting, or travel skills, either because they have physical disabilities, or because they haven't had sufficient prevocational training. In 1982, parents and professionals serving on the ARC Education Committee in San Francisco obtained data from the school district showing that more than 200 severely disabled students would graduate from the San Francisco school system during the next three to five years. They also found that no programs other than adult day care were prepared to accept these individuals. As a result of receiving this information, ARC is now working with the school district, the local Developmental Disabilities Council, and other adult service providers to stimulate program development, and to design a workable transition plan for these students.

Working with specialized service providers is just one way in which parents can mobilize community agencies into providing full services. Parent involvement is also essential for ensuring that severely disabled people will be included in other agencies serving the public, (e.g., recreational programs sponsored by the YMCA or the community Parks and Recreation Departments.) Later sections of the manual (see Chapter 4) thus present strategies for generating a trainer of trainers model that involves parent volunteers in working to mobilize school and community agencies.

D. The First Step: Forming a Parent Support Group

Starting parent support groups at schools that are integrating severely disabled students is not only the first step in establishing a parent/community program, it is also a focal point of such programs for several reasons. First, it's likely that parents whose severely disabled children are within a given age range and functioning level will share common priorities and needs. Second, parent groups representing one or two classes of severely disabled students at a school are of a manageable size for carrying out group activities, and establishing friendships or supportive relationships. A third point is that school site administrators are likely to become involved in the parent activities that occur at their site. The corollary to this is that the support group will have direct access to -- and could become a subcommittee of -- the PTA at the school site. Still another plus for using the school site as a base for the support group is that teachers and parents can coordinate home-school interventions. And, finally, parents' ongoing contact with the school that their child is attending means that they can be directly involved in inservice or awareness-level training for regular education staff and for students who are unfamiliar with severely disabled children.

Because the support group is an essential part of the approach that Project REACH found most effective, the next chapter of the manual explains in detail how to form the group and what its functions are likely to be.

Later chapters of the manual discuss parent advocacy work, training, and outreach and awareness education in the community. Detailed information is also provided on how to mobilize community service agencies and develop a trainer of trainers model.

2. PARENT SUPPORT GROUP

A. Choosing a Parent Facilitator

The person who acts as facilitator of the parent support group may be a parent, or a professional who is involved with severely disabled students. If the facilitator is a professional, we strongly urge that you select a co-leader from the group of parents you're serving, or from each school site. This is a way to ensure that activities will continue if the professional is transferred or funding for a professional's services is no longer available. You may also find that a parent co-leader will be more sensitive to parental needs and concerns, and may be more proficient at recruiting other parents for active involvement.

Professional facilitators may come from any one of several disciplines. If the facilitator comes from within the school, he or she may be a classroom teacher of students with severe disabilities, a paraprofessional, a school psychologist, a guidance counselor, or a social worker. In some cases, special education administrators (i.e., program specialists, or supervisors), may be able to assume this role. People outside the school district who could serve this function might include: caseworkers (from disability service agencies or regional centers) who work with several families within the school district, or university personnel. The latter might become involved so that they could initiate an internship program or practicum* for student teachers, student social workers, student clinical psychologists, or related social service professionals.

Table 1 on the following page presents the advantages and disadvantages of utilizing each of the people listed above.

B. The Role of the Parent Facilitator

The specific functions that the facilitator assumes will depend on the parents involved in the program. This statement may appear to be self-evident, but it's rare that parent programs are established on the basis of the same kind of individualization and needs assessment that are provided for our students with severe disabilities. Usually, parent involvement programs reflect professional priorities, which may or may not match those of the parent (Lynch, 1981; Vincent, Dodd & Henner, 1978). The resulting lack of parent participation is then attributed to

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* See the **Glossary**

Table 1

Advantages and Disadvantages of Choosing Parent Facilitators from Various Disciplines

Facilitator	Advantages	Disadvantages
Parent	Experience. Sensitivity to other parents' needs, priorities. Best advocate for child. Effective parent recruiter. High credibility. Able to offer parent-to-parent support.	Possible lack of familiarity with school district's system, procedures. Possible need for training in areas such as legal rights, or issues (i.e., normalization,* integration*).
Within-District Professional:		
Teacher	Mutual communication, sensitivity increased between teacher and parents. Home-school coordination improved; ecological inventory* possible; opportunity to train parents in school objectives, and to tailor school program to families' environments.	Possible over-emphasis on classroom programming &/or teacher priorities. Possible conflict since parent concerns may have to do with teacher. Advocacy difficult; teacher works for system. Time constraints may prevent teacher participation.
Psychologist	Mutual communication, sensitivity increased. Psychologist's awareness of severely disabled students' needs and potential increased.	Psychologist often unfamiliar with severely disabled student outside testing situation. Possible overemphasis on counseling of parents. May not be familiar with range of community resources. Same advocacy problem as teacher.
Social Worker	Same as psychologist, and: familiarity with community resources (e.g., respite care, after-school recreation)	Social worker may be unfamiliar with severely disabled students' needs and appropriate programming. Caseload often high; may prevent participation. Same advocacy problem as above.
Administrator	Mutual communication and sensitivity increased. His or her participation demonstrates school's commitment to parents.	Administrator may not have experience with severely disabled student population. Same advocacy problem as above. Time constraints may prevent participation.
Paraprofessional (teacher's aide)	May welcome opportunity for increased "exposure" and responsibility. May be especially helpful in rural districts where a variety of professionals not available.	Teacher may not be comfortable with paraprofessional having direct contact with parent.
External Professional:		
Agency caseworker	Caseworker's familiarity with school programs and severely disabled students' needs increased. Caseworker usually familiar with community resources and individual family's needs. Can be effective advocate within school system (because they're not employed by the district).	Possible lack of familiarity with school system. Large caseload may prevent participation; agency may not view this as part of role. Caseload of families being served may have needs too disparate to allow them to function as group.
University Personnel (from Special Ed., Social Work or Psychology department	School district-university communication and coordination increased. Can be effective parent advocate. Supplies additional personnel for district. Aids university by supplying sites for internships, practica*. Can acquaint parents with latest techniques.	Possible lack of familiarity with district procedures, budgetary limits, etc. Possible unfamiliarity with classroom programming. May be viewed as threat by both district and parents. May be no college or university in close proximity to the school district.

* see the Glossary

parental apathy, or lack of concern. What is looked upon as apathy may actually be a real lack of knowledge about the school system, the roles of professionals within that system, and what educational programming would be appropriate for the child with severe disabilities. Parents may also fear that their concerns and needs don't correspond with those of other parents.

To make sure that parents will become and stay involved in the group, the first priority of the facilitator is to conduct needs assessments with the parents who will form the support group. In our work with REACH parents, we identified several areas of need:

- knowledge of legal rights
- knowledge of school district procedures or protocol
- information about district personnel and their roles
- information about community resources (e.g., respite care, medical services, recreation programs, sibling support groups, vocational opportunities, etc.)
- information about classroom programming

C. Conducting Needs Assessments

You may want to carry out your needs assessments by interviewing parents at an initial group meeting or by mailing out questionnaires. Sample needs assessments or inventories that REACH utilized to interview parents in person or by mail are presented on the following pages. The parent interest inventory was most effective when it was used in one-to-one interviews or small group settings. It could be administered by a parent group facilitator, or by classroom teachers who planned to be actively involved in parent activities.

D. Obtaining and Analyzing Needs Assessment Data

Now comes the hard part: convincing parents to fill out the needs assessments, and analyzing the results. During the REACH Project, we found that some parents feared that a printed "assessment" instrument would reflect on their parenting ability; others were inexperienced at rating various priorities, and concerned about putting things into writing. If you receive several blank forms back from parents, or notice that they're reluctant to participate in this activity, you'll know that some of these anxieties are occurring. Below are some ways you can avoid the mistakes we made in initiating contacts with parents:

- call it a "Parent Interest Inventory" or some other term that's less threatening than "assessment".

Project REACH

PARENT INTEREST INVENTORY

1. General Information Sheet

Name of Child: ____________________

Class Location: ____________________

Teacher: ____________________

Length of time child has been in program: ____________________

Parent(s)' Name(s): ____________________

Address: ____________________

Phone: __________ Business Phone: __________

Siblings? __________ How many? __________

Name(s): ____________________

Age(s) : ____________________

Sex: ____________________

Date of Initial Meeting between Parent and Facilitator __________

Place: ____________________

People in Attendance: ____________________

____

____

____

Agency(ies) involved with family:	Worker's name:
____________________	__________
____________________	__________
____________________	__________

PARENT INTEREST INVENTORY - Page 2

2. Parent Inventory

A. Please rate the following areas for service according to their importance to you:

	Not Important	Somewhat Important	Very Important	Not Important now, might be later in year
1. Training in classroom objectives and strategies for home use.				
2. Help with managing behavior of child (e.g., temper tantrums, refusal to participate in activities, etc.)				
3. Suggestions for home activities for child and/or referral to available after-school services.				
4. Training for brothers and sisters of student.				
5. Assistance with district procedures (e.g., Individual Education Programs (IEP) conferences, legal rights, parent committees, transportation).				
6. Meetings for groups of parents (see section B. below).				
7. Information about community resources (e.g., advocacy groups, respite care, etc.)				

B. 1. Do you presently belong to any parent group? Yes ____ No ____
What kinds of activities is the group involved in?

2. Would you like to belong to a parent group? Yes ____ No ____

3. How often would you want the group to meet?

every two weeks____ once a month____ other______________________
specify

4. What time of day or evening? __________________

C. What would you think would be the most helpful type of group meeting format? If checking more than one, please rate priorities (1 = most helpful, 2 = somewhat helpful):

___ group meetings with parents of disabled students at my child's school to share information on concerns of interest to majority (e.g., meetings might include training sessions on integration or IEPs; workshops to make home games, materials, etc.).

___ group meetings of parents of disabled students and parents of regular education students to work together on integration activities, and other school events or problems.

___ small group discussion and workshops on topics selected by participating parents.

___ other (please specify)____

____

___ I am not interested in any type of group meetings.

D. 1. Do you need transportation in order to attend group meetings? ______

2. Do you need childcare while attending group meetings? ____________

3. Would you like the idea of having group parent meetings in parents' homes? ________________ If so, would you be interested in having one at your home once every few months? ____________________

E. Topics I would come to a meeting to learn more about (check as many as you want):

my legal rights as a parent ____
how the school district works ____
how to be more assertive at an IEP meeting ____
how the regional center works ____
vocational programs for my child as an adult ____
background and reasons for integration ____
awareness education training for integration ____
how I can help integration work ____
community agencies that can help meet my needs ____
functional, age-appropriate curriculum for my child ____
other: __________________________
____
____

- if you're doing <u>individual interviews</u>, ask the parent where he or she would like to meet you (e.g., at a coffee shop or whatever). Don't expect parents to invite you into their homes right off the bat. Home visits can seem very anxiety-producing to many parents.

- be clear about the purpose of the inventory -- i.e., that you're interested in finding out whether parents would like to be in a support group, and you want to make sure that it's the <u>parents</u> who decide what that group will do!

- If you and/or the parents don't have time for individual interviews, plan to use part of your opening group meeting to fill out forms together. You can read the questions aloud, and ask parents if they'd like to suggest any additional categories of information. Or, you can use the form as the basis for initiating a brainstorming activity on the whole group's priorities. (See section E in this chapter for details on the opening group meeting)

When you analyze the parents' answers to your verbal questions or to the written questionnaire, we suggest that you:

- make a large chart on which you can plot the number of parents with transportation, childcare, and translator needs (see the following page). Next, note parent schedules, and when, and how often they want to meet. List how many currently belong to groups for parents of disabled children, or advocacy groups, and how many said they weren't interested. Then list all the possible activities you asked parents to rate, according to their level of interest. Are there any common needs? What seems to be of highest priority? How many of these areas are within your expertise to offer? What community groups can you pull in to help you with topical presentations or workshops?

- write one or two objectives for the group, based on the results of the inventories. Bring these objectives to the next group meeting for parents' reaction. Be prepared to start from scratch if parents think the objectives don't match their concerns. Ask them to write their own objectives!

Parents' Needs and Activities Chart

Needs	Mrs. A	Mrs. B	Mr. C	Mrs. R	Mr. W	Mrs. T	Mrs. L	Mrs. N
childcare	x		x	x			x	x
transportation	x	*	x	*	x	*	x	x
translators	x	*					*	x
free Monday evenings		x	x	x	x		x	x
free Tuesay evenings						x		
free Wednesday evenings								x
free Thursday evenings								x
free Friday evenings								x
want to meet weekly					x		x	x
want to meet monthly		x	x	x		x		

* can provide translation, transportation, etc.

E. Arranging the Opening Meeting

The needs assessment you do should take place over no more than a two-to-four week period, so that initial interest in the group doesn't dwindle as a result of inactivity, or a lack of direction. You may also want to schedule one meeting at which you do the interviews, then call a more formal opening meeting. Because this meeting will establish your credibility as a good organizer, it's crucial that you pay attention to the areas we describe below:

- Invitations. If possible, invitations should be mailed to parents, rather than sent home from school with students, so that the invitations won't be lost. Mailing them also means that they'll reach parents well in advance of the scheduled date and time. At least three possible dates and times should be offered to parents in order to accommodate their work and childcare schedules. Follow up the invitations with phone calls to encourage parents to attend, shortly after you think they've received the invitations.

- Translators. If limited or nonEnglish-speaking parents are to be part of your support group, have the invitations translated for them, and provide translators at meetings as well. If funds are not available for this purpose, try contacting caseworkers working with the family for suggestions, or to ask that the caseworkers attend. Alternatively, bilingual high school or college students can be asked to act as volunteer translators, or, another bilingual parent in the group might be willing to translate for the family. Frequently, teenaged siblings of the severely disabled student may be bilingual, and can accompany parents to group meetings. The family's church might also be able to provide translation.

- Childcare. If you haven't already completed your needs assessments, and don't know whether or not childcare is essential to parents, enclose a stamped postcard (or a tear-off slip to be returned to school) in your invitations that allows parents to indicate whether or not they do need childcare, or simply note that childcare will be available at the meeting itself.

Childcare is easy to provide if funds are available for this purpose. Classroom paraprofessionals or student teachers may be recruited, and reimbursed. If no funds can be found for this purpose (as is highly probable), volunteers may again be required. You might try recruiting foster grandparents if there are any who work with the class. At an integrated middle school or high school, peer tutors (i.e., students of the same age or older who work with the severely disabled students) might be recruited for this purpose. Nondisabled siblings are another possibility. If these resources are unavailable, another alternative is a rotation system, where parents attending this opening meeting take turns spending brief periods with the children present, preferably in a room adjacent to the meeting.

- Transportation. The parent facilitator may need to take an active role in assuring that all interested parents have some means of transportation to the meeting. Bus schedules may be included with meeting announcements, or parents can be asked in the follow-up phone calls whether they need a ride, or could offer one to someone else who lives near them. Since you need a written release to distribute parents' phone numbers to each, it may be necessary for you to make all the arrangements yourself. At the first meeting, be sure to ask parents to sign a release and/or exchange phone numbers.

- Refreshments. Providing snacks and beverages is important, especially for evening meetings, when many parents may have come directly from work, and may not have had time for dinner. For the initial meeting, the facilitator(s) can bring snacks and beverages, or can ask parents to volunteer to bring something. Signing up to bring a snack to future meetings helps parents feel that they're contributing to the group, and lends a more relaxed social atmosphere to the meeting situation.

- Program organization. You'll need to have a clear agenda in mind for this first meeting, since the future success of the program depends upon how beneficial parents perceive this initial session to be. (During the REACH Project, one parent never returned after the first meeting, explaining that she "hadn't learned anything new".) Keep in mind that it's an effort for the parent of a severely disabled child or young adult to come out for an evening meeting after a long day. It can also be difficult to travel to the child's school during the day for a meeting. Professionals often resent the low attendance at parent meetings, especially when they've given up their own time to be present. But if you remember the possible reasons for low attendance, (e.g., transportation, childcare, work schedules), you can plan meetings accordingly, and ensure that parents will feel that it's been worthwhile to participate.

Before meeting the parents, you should also observe the students and classroom program to familiarize yourself with the children, and to have some idea about their needs and concerns. It's important, too, to meet the principal or primary administrator, to learn the school's procedures, and to acquire permission for using meeting space in the school. And, it's equally important to plan the agenda of the first meeting with the classroom teacher, whether or not the teacher will be present at the meeting. You'll need to know what the teacher's objectives are for parents, as well as his or her attitudes toward them. Are they a new group to this teacher? Has the teacher had any contact with them? Have any parents come to school to observe the class? Have they ever been involved in school or community parent organizations in the past? Does the teacher think they're likely to become active? Why or why not? What does the teacher see as possible areas of parent concern? How involved does the teacher want to be in the support group?

The answer to this last question will undoubtedly affect the nature of the parent program. The brief case history below of School #1 in San Francisco illustrates how one program developed without teacher involvement:

> Although the teachers of both classes of students with severe disabilities stated before the first meeting that they chose not to be involved in the parent program, they attended the initial meeting -- which was an open house at the beginning of the school year. Both teachers presented general information about the classroom program, the daily schedule, and their plans for integrated activities with regular education students at the school. The parent facilitator presented information about her role within Project REACH, and about REACH's awareness training for the regular education students. After she explained the goals of integration, parents watched a film that REACH used as part of inservice training for regular education studens and staff (see the Appendix for a description of the film, David.)
>
> The rest of the meeting was devoted to a discussion of parent priorities for future meetings. The facilitator explained that she would be the staff person present at these meetings. Several topics were raised by the parents. Among those mentioned were legal rights, after-school programming, and respite care. Consensus was reached on a date for the next session, which would be a topical presentation and discussion regarding legal educational rights.
>
> From the outset, this parent group focused on issues beyond the realm of the immediate classroom. This appears to have resulted from the fact that the facilitator was not their child's teacher, and therefore was not intimately familiar with each child's Individual Education Plan (IEP) or the daily events at the school. While it would have been beneficial to have the teachers actively involved in meetings, it wasn't essential because parents were concerned with community as well as school issues. The group operated somewhat independently of the school, branching out into exploration of after-school programs, holding a potluck dinner at the school, calling and writing letters to other parents to encourage their involvement. They weren't dependent on school personnel to invite them to a meeting. By year's end, one group of three Latino families was in frequent communication with each other between support meetings.

This example isn't intended to give you the impression that Project REACH advocated that teachers not participate in parent support groups. Rather, the point was to show that a viable group can be established even when the teacher of severely disabled students chooses not to be involved.

1. Planning the Agenda

The format and agenda for the first meeting will depend on staff persons involved, the type of information you've acquired through the individual inventories, and the time of the year (e.g., at the beginning of the year, parents would need much more basic information than they would after a few months, and teachers would be more likely to attend so that they could meet the parents, and give them information). When setting up the first meeting, you should consider some basic principles that professional meeting facilitators generally follow (Rogers, 1969). First, set aside time for an opening greeting, during which each parent has the opportunity to introduce him or herself, and say a few things about his or her child. Staff people and the facilitator should do this, too, by giving a brief "bio" of themselves, and their experience with students who have severe disabilities.

The rest of the agenda should be introduced at this time, including who will be presenting each segment, what the topics are, and when opportunities for discussion will occur. The facilitator may open by describing parent support groups he or she has worked with or observed, after which the facilitator can suggest that the last part of the meeting be reserved for a discussion of this group's direction. We found that parents were discomfited by the idea of spending a whole meeting discussing the parents group or being asked what they wanted to do, since their expectation was that one goes to a school meeting to learn something, not to be involved in a process of self-discovery.

It's also important to make it clear to parents when you send out invitations that there will be a topical presentation during this initial meeting. At one REACH school, we sent out an invitation to set up a support group, which said that the parents would decide on the agenda. Only one-fifth of the parents attended, and those parents who did come said that they were sure that the absent parents felt threatened by the vagueness of such an invitation. They suggested having an informational presentation planned for the initial meeting, followed by a discussion of group priorities and future directions. We took their advice, and we held a subsequent meeting with guest speakers from the local Association for Retarded Citizens, who discussed vocational opportunities for young adults with severe disabilities. This meeting was very well-attended by the parents of the severely disabled teenagers from that school.

2. Establishing Group Priorities, or Where Do We go from Here?

A support group for parents of students with severe disabilities can have multiple functions. As we've mentioned, these may include, but are not limited to: advocacy-action, training, community outreach and awareness education, agency mobilization, and networking. However, to carry out any of these efforts, parents will need information, and should have the oportunity to identify issues they want to explore further before deciding on a course of action. The first task of the group will thus be information sharing and exchange.

Toward the end of the first meeting, you may find that a brainstorming activity can help initiate the information-sharing process. After dividing into groups of four or five, parents can list all the items that come to mind as areas of concern, or topics they'd like to know more about. This is a ten to fifteen minute activity, during which the facilitator circulates among the groups, and a parent recorder lists every suggestion on large charts, or on butcher paper. When the groups reconvene to report on the results of their brainstorming session, areas of duplication are noted and a master list is compiled. The group then places the topics in order of priority.

If, for example, legally-mandated educational rights seem to be the first priority, the facilitator will want to ask whether any parents have attended previous workshops on the subject, have received any written information from the school district, or have communicated directly with any advocacy organizations. You can also ask whether there was anything lacking in these presentations, and what specific issues are of concern (e.g., evaluation, due process, etc.).

There may be a parent within the group who'd be interested in co-leading a workshop on the topic with the facilitator. You should encourage this participation, since the less passive the group is from the beginning, the more successful and cohesive it will become.

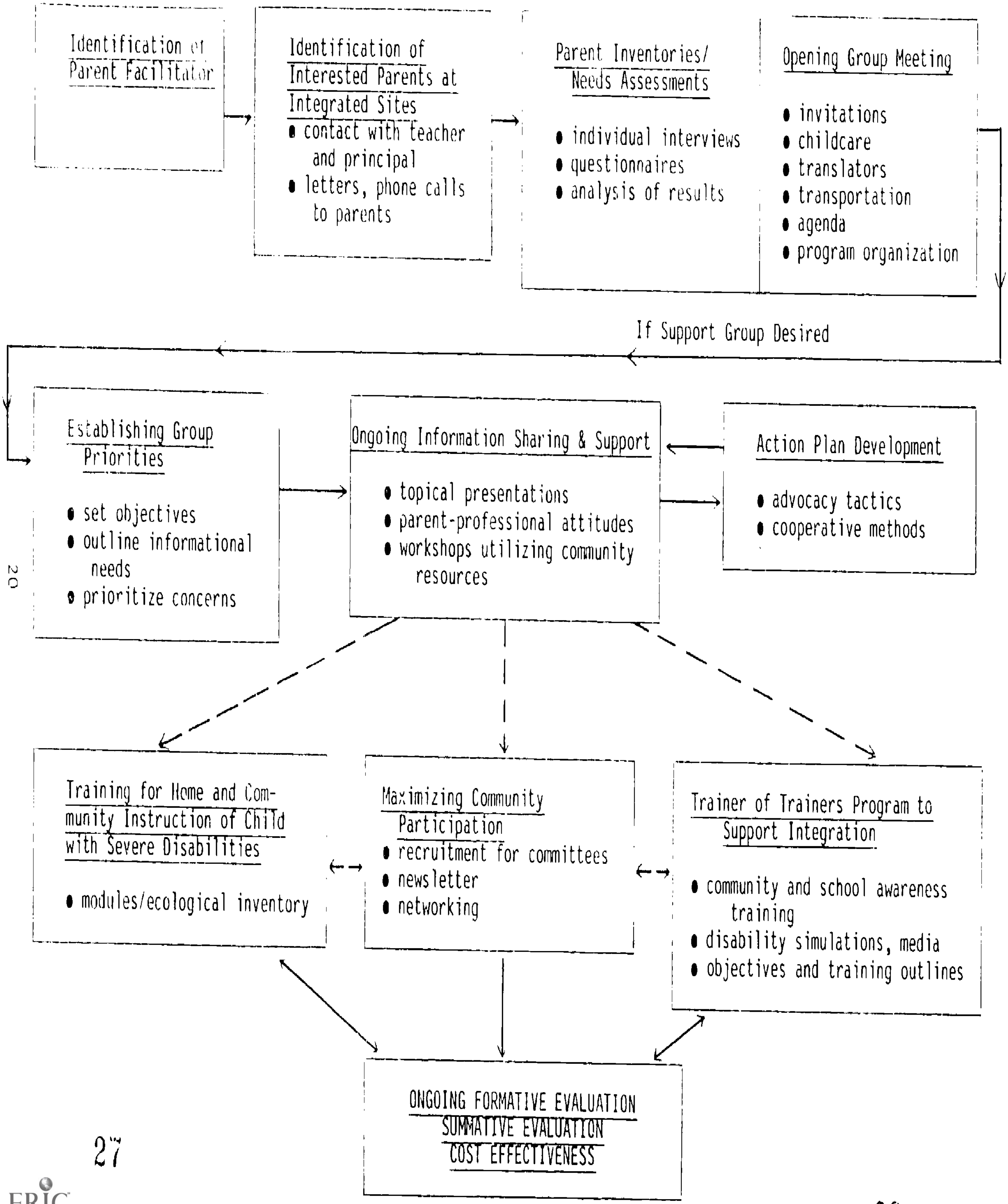
If the group members are unsure of their level of information about a topic, two avenues are open to you. In the case of legal rights, you may want to make use of an existing survey of parent knowledge that can be administered individually in a brief period (see the Mt. Diablo questionnaire in the Appendix). With other issues, such as respite care, or recreational or vocational programs, you can simply ask questions orally to find out the information level of the group.

3. Closing the Meeting with Lists of Priorities, a Date for the Next Meeting and A Phone Chain

Before you close the meeting, each parent should make his or her own list of the priorities that the group agreed upon. A date for the next meeting should be set, and details such as transportation, childcare, and refreshments can be discussed at this time. The group should then decide how often it wishes to meet: once a month, once every two or three weeks, or otherwise. Parents might exchange phone numbers or release their numbers to a designated parent, who will serve as co-leader of the group or as "room mother" or "room father". This parent can then devise a phone chain before the next meeting, so that parents can call other parents to encourage them to attend. You as the facilitator should also plan to send out a written reminder in advance of the meeting. Before doing so, you should have planned the next topical presentation, either with a parent co-leader, a guest speaker, or on your own (see the Appendix for "Resources for Topical Presentations and Parent Support").

The chart on the next page summarizes the steps in parent group formation that we've discussed in this chapter. It also shows how the group's activities are interrelated, once the members have become involved in sharing information.

Project REACH Parent Involvement Model



3. THE ACTIVITIES OF THE PARENT SUPPORT GROUP

A. Information Sharing and Support

As we've stressed, giving parents accurate and comprehensive information is one key purpose of the parent involvement program. Resources to aid the facilitator in preparing and/or presenting appropriate material are usually available in the immediate community, or they may be obtained by writing to specific referral addresses. (See the section of the Appendix entitled Resources for Topical Presentations and Parent Support for these addresses). As you probably realize, the group will need to continue to acquire new information as it moves into new areas. Consequently, the information sharing process shouldn't be regarded as a set phase with a beginning, and a termination point.

Offering group members support is another integral aspect of maintaining any group. It is crucial that each parent in the group feel that his or her opinions and concerns are valued by the total group, and by its facilitator. This isn't a simple task, since the group is likely to be diverse, with a variety of ethnic groups represented within it, as well as a cross-section of educational and socioeconomic levels. Many professionals tend to center their efforts on the more articulate and highly educated parents of students with severe disabilities. The result is that the less informed or unassertive parent, who may be in greater need of support than the others, feels alienated and "left out".[2] It's easy to see why professionals have followed this trend; many have felt that the more articulate and aware the parents are, the greater the chances the parent program has for success (Kroth and Simson, 1977). This type of thinking has simply widened the rift between parents and professionals, and prevented constructive cooperation. To aid you in examining your attitudes toward parents, you may want to complete the exercise Kroth and Simson (1977) have written for professionals. We've included it on the next pages because we recommend that you be aware of your attitudes toward parents before beginning the support group. If you want to encourage parents to value each other, and provide each other with support, you'll need to know whether you're acting to increase the likelihood that parent to parent support will be offered or whether you're likely to unconsciously favor the more educated parents (for additional information on group processes, we recommend Freedom to Learn by C. Rogers, published by Charles Merrill, 1969).

Figure 1

Parent Conference As a Teaching Strategy

(Adaptation of Kroth, R., Simson, R.L.
Denver: Love Publishing, 1977)

Procedure: Place a check in Column A next to those items that pertain to you. Then, if you want a further check on how others see you, cover Column A or fold it under, and give it to someone who knows you well (another teacher or supervisor), and have him or her mark Column B. This method is not as accurate as actually tallying behavioral data yourself, but if you act on your values, others are usually aware of it. Column C can be used by a third person, or you can use it at a later date to see if any change has taken place.

ARE YOU A TEACHER WHO...

A	B	C		
			1.	never admits to a parent that you're wrong?
			2.	has a sense of humor in a conference?
			3.	lets parents smoke in a conference?
			4.	serves coffee to parents during a conference?
			5.	doesn't have any favorites?
			6.	shows expression and emotions in a one-to-one conference with parents
			7.	shows expression and emotions with groups of parents
			8.	starts conferences or parent meetings on time?
			9.	stops parent meetings at a scheduled time?
			10.	has conferences in parents' homes?
			11.	compares students with their older siblings?
			12.	finds it hard to say "I don't know" to parents?
			13.	talks less than 50% of each conference?
			14.	talks about your own problems and solutions in conferences?
			15.	sits behind a desk during conferences?
			16.	enjoys parent conferences?
			17.	has examples of children's work to show parents?
			18.	calls parents when things go well with their child?
			19.	sends notes home when children have behavioral problems?
			20.	uses grades to keep students in line?
			21.	has ever had a principal sit in on one of your conferences?

Figure 1 (continued)

A B C

_______ 22. finds yourself criticizing more than praising your parents?

_______ 23. has ever had parents over for a meeting at your home?

_______ 24. feels that parents have lost the respect of their children?

_______ 25. feels that parents have lost control of their children?

_______ 26. finds yourself physically drained at the end of a series of conferences?

_______ 27. has parent group meetings?

_______ 28. has strong negative feelings about certain racial or sexual groups

_______ 29. prefers to have conferences with fathers rather than mothers?

_______ 30. studies a child's folder and past achievements before a conference

_______ 31. argues with parents?

_______ 32. feels intimidated by parents?

_______ 33. demonstrates to parents effective ways to work with their child?

_______ 34. likes to problem-solve with parents?

_______ 35. involves parents in planning for their child?

_______ 36. encourages parents to visit class during class sessions?

_______ 37. uses parents as aides in the class?

_______ 38. does not want parents to teach their own children?

_______ 39. is honest with parents?

_______ 40. listens to parents?

_______ 41. has parents call on the telephone to your home in the evening?

_______ 42. is supportive to parents?

_______ 43. sends home daily written news?

_______ 44. prepares handbooks or handouts for parents?

_______ 45. has good attendance at conference time or for group meetings?

_______ 46. has students sit in on conferences with their parents?

_______ 47. talks about other teachers to parents?

Some problems that make it difficult for the group to support each other are easy to recognize. Among these is the noticeable tendency of one or more parents to dominate the group, by talking constantly, interrupting others, and preventing others from speaking. The facilitator must be prepared to remind these parents of the presence of others, to ask them to give Mr. Brown a turn to respond, or to suggest that they keep their remarks brief, while thanking them for their contribution.

It's also likely that there will be parents who rarely contribute, especially if the group is larger than four or five people. The facilitator will need to direct specific questions to these parents. You can ask them to comment on others' statements, or ask if they agree, etc. To encourage all group members to participate, it may be necessary to suggest a discussion format where each parent is provided with an opportunity to comment in turn. This discussion circle is somewhat artificial and cumbersome, but it should become less necessary as parents become more familiar with each other.

When limited English or nonEnglish speaking parents are present with a translator, the group will need to be reminded to allow time for remarks and presentations to be translated. Guest speakers should be told that translators are present so that they can pace their presentation accordingly -- and so that they'll understand why someone else is speaking at the same time as they are.

In evaluating your own attitudes toward parents, and deciding how you can be as supportive as possible, you should be aware that support can mean a variety of things to the different parents within the group. To one parent, it may mean meeting another parent with a severely disabled child who is from the the same ethnic group, or who literally "speaks my language". To another, it may mean an opportunity to discuss arranging a residential placement for their severely disabled child, with all the mixed emotions inherent in such a decision. To a third, it may mean the chance to develop friendships with other parents, and bring their children together for social activities. To many, "support" may translate into an opportunity to learn more about the school environment, the rationale for specific activities, and the strategies for supporting or changing these. A parent alone may frequently feel powerless or inadequate when dealing with a large school district. A group of parents will discover quickly that their actions can have a major impact on that district. Their mutual support, accompanied by their acquisition of accurate information about their areas of concern, will greatly increase their ability to act in a way that will produce positive change.

The major questions to keep asking yourself as a facilitator are:

- am I talking more than 10-15% of the time in "discussion"?

- do parents direct all their remarks to me?
- who is deciding group objectives at each session?
- who is evaluating the effectiveness of each session?
- how many parents know other parents' names and use them?
- how are disagreements resolved by the group?

B. Advocacy-Action

Jan Elster, author of Whose Community is it?, developed by Project Co-Action of the San Francisco Association for Retarded Citizens, defines an advocate as "someone who speaks for the rights of others . . ." (1982). Clearly, parents of children with severe disabilities are the ideal advocates for their children. No one has a stronger commitment to their well being.

1. What do advocates do? How does a support group advocate?

It might appear that advocates are only needed when disabled children and youth are in danger of losing key services. Or when new legislation is required. Or when new legislation may endanger the current status of severely disabled students. But, while these are certainly crucial current concerns, advocacy is not limited to these areas.

In San Francisco, a variety of issues arose during the 1981-1982 school year. REACH parent groups, the Community Advisory Council for Special Education, the Association for Retarded Citizens Education Committee, and other parent-professional advocacy organizations addressed the following needs and issues:

- the need for new after-school recreation programs,
- the location of integrated classrooms for severely disabled students in the San Francisco Unified School District (i.e. defining appropriate sites),
- the need for inservice education for parents,
- paraprofessional to student ratios,
- need for paraprofessionals to accompany students on schoolbuses,
- the length of the summer school day (which was considered not long enough)
- the continuation of a classroom at a successful integrated site,
- the need for awareness education in the community,
- the need for increased adult vocational opportunities for people with severe disabilities.

These are merely a handful of the concerns that a given community or school district might face in a ten-month period. But all these needs or obstacles can have an immediate impact on the day-to-day quality of life of the severely disabled student and the student's family. Choosing just one of these issues for the parents' initial advocacy-action efforts may be far more meaningful to parents who are just "getting their feet wet", than a letter-writing campaign to their state or federal representatives asking for increased funding, or maintenance of federal regulations like PL 94-142. The letter-writing activity is likely to meet with more enthusiasm from parents once they've experienced local or personal success through their advocacy efforts.

2. Designing a Plan of Action

Once parents have decided on an issue or unmet need, they can figure out what their plan of action will be. The Coordinating Council for Handicapped Children recommends several effective action strategies in their manual, How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies. They list the following types of action as dramatic ways to bring issues to the attention of the public or to exert pressure on bureaucracies:

- a mass public information campaign,
- a march on schoolboard, city hall, state legislature, etc.,
- a public rally,
- a boycott,
- a sit-in,
- a mail campaign,
- a telephone or telegram campaign,
- a public hearing,
- a bus/car cavalcade,
- picketing.

(Des Jardins, C., 1980: p. 39)

These strategies are especially suitable for dealing with such major problems as drastic personnel cuts in a school district program, new legislation that has a negative impact on services, the forced closing of a program, or cutbacks in related services. But these are not the only actions your parent support group can take, and some may be inappropriate for certain problems. Frequently, a parent group of ten to twelve people may also feel that they lack the resources to engineeer a major campaign.

If dramatic strategies are best limited to dramatic situations, what other alternatives are there? For starters, before resorting to picket lines or rallies, more subtle methods should be attempted, such as meeting with important decision-makers. Discussing policy with those powerful enough to change it may be equally effective in some cases. We should remember that the spirit of P.L. 94-142 is one of parents and professionals (or school districts) working together cooperatively. Wherever possible, it should be our goal to cooperate, rather than set up an adversarial relationship. The case history below presents an example of working for change by presenting information and proposing solutions to key decision-makers:

> School #2 in San Francisco was a highly successful integrated elementary school, that had started with one class of severely disabled students, and added a second class one year later. Regular education staff and parents were strong advocates for the program. Regular education students were active participants in "peer tutoring" and "special friends" programs (for further details on these programs, see another REACH publication: the Awareness and Inservice Manual). Parents of the severely disabled students were extremely supportive of the program too, despite the somewhat inaccessible physical plant of the school. Positive attitudes in the school had resulted in ways to "get around" arcitechtural barriers.
>
> After two years of carefully structuring integration efforts, the school district decided that the two classes for severely disabled students should move to more accessible sites. No-one at the school had been consulted, and staff and parents were extremely upset. One immediate reaction was to consider launching a major mail campaign to the Board of Education, and to the administrators of Special Programs, followed by a presentation at a Board of Education meeting. School #2's principal suggested an alternative plan: invite the administrators in question to a meeting with regular and special education representatives from school #2. At this meeting, the parents could present proposed solutions and arguments in favor of the classes remaining where they were. The principal pointed out to the staff and parents that the Board of Education decides policy, and could, at most, recommend a delay in the move. The special education administrators were the decision-makers in this case.
>
> The parents and staff decided to follow the principal's plan. A meeting was arranged, and in the meantime, several parents of regular and special education students wrote to or called special education administrators to explain their point of view. The plan was a success -- both classes remained at school #2.

School #2's solution is an illustration of how pressure may be exerted on a school district without damaging working relationships between parents and key administrators. We recommend using these subtle tactics whenever feasible, to preserve good working relationships, and to ensure that the stronger tactics will be effective when you need them -- that is, that they won't "lose their punch" through overuse. A major letter campaign or public rally is effective when matched with an issue that will affect large numbers of severely disabled students. Since it's not a simple task to rally large numbers of parents to write letters, or take time off from work to appear at a rally, or join in other forms of mass protest, reserve these strategies (and the all-out effort you'll have to make to initiate them) for issues where across-the-board support must be demonstrated.

3. Some Alternative Advocacy Tactics

In addition to requesting a meeting with the administrators involved in a decision affecting their severely disabled children, parents may want to try the following pressure tactics:

- arranging small group meetings with key Board of Education members
- having as many parents as possible write a petition to the administrator
- having one or two parents request speaker's cards at a board meeting and address the board on the issue
- bringing the issue to the attention of the Community Advisory Council for Special Education in the district

A list of additional resources for advocates and parent advocacy groups appears on the following pages. The list was compiled by Jan Elster of Project Co-Action (of the San Francisco Association for Retarded Citizens). We've also included the exercise sheets that Project Co-Action used in a series of advocacy training workshops they gave nation-wide to aid you in laying out your own parent group's plan of action.

ADDITIONAL RESOURCES FOR PARENT ADVOCACY GROUPS

1. Orientation Training for Community Care Residence Operations; Developmental Disabilities, the Resident and You. Although this manual is geared toward residence operators, it contains a thorough treatment of advocacy, and how individuals can be taught "self advocacy".

2. Avenues to Change, Booklets I-IV, National Association for Retarded Citizens, Arlington, Texas. The handbooks are designed specifically for use with individuals with mental retardation. However, they're useful for anyone dealing with advocacy since they touch on various topics, from the history of advocacy to guidelines for the role of the advocate.

3. A Coordinators Guide for Training Citizen Advocates, Avenues to Change, National Association for Retarded Citizens, Arlington, Texas. This basic training guide covers such areas as attitudes towards individuals with disabilities, normalization, the roles and responsibilities of citizen advocates, resources, and communication skills.

4. Advocacy Systems for the Developmentally Disabled, Research and Training Center in Mental Retardation, Texas Tech University, Lubbock, Texas. A collection of speeches on various models of advocacy and preliminary plans by states for developing advocacy programs. The plans resulted from a joint conference between the Developmental Disabilities Office of the Office of Human Development and the Research and Training Center in Mental Retardation.

5. Citizen Advocacy, Texas Association for Retarded Children, Inc., 1973. A manual for providing general procedural guidelines that can be used in establishing an Operational Citizen Advocacy Office at a local community level.

6. "I Can Help Myself", National Association for Retarded Citizens Research and Demonstration Institute, Arlington, Virginia. A basic illustrated manual that may be used with trainees for explaining the role of citizen advocates.

7. Self Advocacy Training Module I, Trish Brown. Sonoma County Citizen Advocacy, Inc. A training manual with exercises that define self-advocacy, and ways for advocating for rights.

8. The Rights of Mentally Retarded Persons, Freidman, Paul R., New York, 1976. An American Civil Liberties Union handbook. A guide setting forth the rights of people with disabilities under present law. The book offers suggestions on how to protect these rights.

9. The Parent/Professional partnership series: 1) "The Right to Education": 2) "Classroom Programming"; and, 3) "The Partnership". This is a guide to the Education for all Handicapped Act, 94-142, 1974, and offers suggestions for attaining services.

Note: All of the above can be obtained through your local Association for Retarded Citizens, or from the national headquarters of the ARC, 2705 Avenue "E" East, Arlington, Texas 76011.

ADVOCACY ACTION PLAN

ISSUE OR PROBLEM	DESIRED SOLUTION OR OUTCOME	ADVOCATE (one or more)	STRATEGY

ADVOCACY ACTION PLAN
(continued)

ACTIVITY	WHO NEEDS TO BE INVOLVED	TARGET DATE OR TIME

4. How to Get What You Want by Being Assertive

The Coordinating Council for Handicapped Children has developed a manual called How to get services by being assertive (Des Jardins, 1980). Excerpts from this manual are included on the following pages.

No matter what advocacy strategies parents use, many people in the parent group may feel intimidated when meeting school personnel.

Even those parents who are most comfortable in the role of advocates for their children may sometimes feel intimidated, if not by school district personnel themselves, by their arguments. Many other parents may need some practice in being more assertive. Below are examples of responses that parent advocates can use in a variety of situations.

15

How a Parent Group Can Help You Be Assertive

" I sometimes feel so alone as a parent. And I feel so overwhelmed when I'm dealing with bureaucracies. Am I the only parent who' going through this?"

NO, YOU ARE NOT THE ONLY PARENT WHO'S HAVING PROBLEMS GETTING SERVICES . Many, many other parents share the same problems, and you need to meet them through a parent group. A parent group can help you be assertive by providing the information and support you need to get services for your child.

A PARENT GROUP CAN:

1. Let you know you are not alone with the problems you are experiencing in getting services for your child.
2. Inform you of your rights under the Education for All Handicapped Children Act (P.L.94-142) and Section 504 of the Rehabilitation Act of 1973.
3. Help you prepare for a staffing, IEP meeting, due process hearing, and other special education meetings.
4. Help you rehearse your presentation when negotiating for services for your child.
5. Provide support at staffings, IEP meetings, Due Process Hearings, and other special education meetings.
6. Help you file complaints with the U.S. Bureau of Education for the Handicapped, the U.S. Office of Civil Rights, when services required by P.L.94-142 and Section 504 are not being provided; or there is evidence that these laws are being violated in any way.
7. Help you lobby for more services, when the service your child needs does not exist.
8. Provide the emotional support you need to be effectively assertive and get your rights.
9. Negotiate with bureaucracies to rectify problems shared by the group.

10. Organize and participate in coalitions to reach mutual goals.

11. Participate with you in marches, demonstrations, picketing to reach your goals - when "going through channels" has failed to get desired results.

12. Give you the self confidence you need to fight for your child's rights.

13. Provide opportunities to share experiences, coping skills, negotiating skills and advocacy skills with other parents.

TO BECOME INVOLVED IN A PARENT GROUP AND/OR MEET OTHER PARENTS:

1. Contact your local chapter of the:

   a. Association for Retarded Citizens
   b. Association for Citizens with Learning Disabilities
   c. Parents of The Hearing Impaired.
   d. Parents of the Blind
   e. United Cerebral Palsy
   f. Spina Bifida Association
   g. Society for Autistic Children
   h. National Alliance for the Mentally Ill

For names and addresses of these parent groups:

Contact CLOSER LOOK, BOX 1492, Washington, D. C. 20013

If there are no appropriate parent organizations in your area, ORGANIZE ONE. Follow steps outlined in HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by The Coordinating Council for Handicapped Children.

21

Assertive Responses For Those Old Excuses

Have you ever heard these excuses? Try out the Assertive Responses listed below the next time you hear them:

1. "There is No Money"

   Remember, there will NEVER be any money if you fall for this old line and accept the fact that there is no money. Whatever money there is can be reallocated and reprioritized. And legally mandated programs must come first.

   YOUR ASSERTIVE RESPONSE:

   "You will have to find the money somehow because the service is required by law, and if it's not provided the school district will lose millions in P.L.94-142 funds and other federal funds for other programs through Section 504 (of the Rehabilitation Act of 1973). This school has many activities that are not required. Since it has money for those activities, it can get money for mandated programs."

   or

   "You must be mistaken Mr...Obviously there is money to pay salaries of people who are employed here. Also, there is money for non-required activities like sports, drama, band. There must be money available for required services under P.L.94-142.

2. "You must be patient. These things take time."

   YOUR ASSERTIVE RESPONSE:

   "I have already waited ______for services. The law clearly states my child must receive services no later than the semester following determination of eligibility. I expect you to obey the law as I do."

3. "You must be realistic."

   YOUR ASSERTIVE RESPONSE:

"I am realistic enough to know that unless my child receives the services he needs, he will not be able to develop his full potential, and he will not be able to provide for his needs. I am insisting on the services he is entitled to precisely because I am realistic."

4. "Don't be so naive."

YOUR ASSERTIVE RESPONSE

"Yes, I'm naive enough to believe public servants should fulfill their responsibilities. That's what my taxes pay them for. I'm naive enough to believe public servants must obey the law like everyone else."

5. "You should be grateful your child is in a program. There are so many others who have nothing."

YOUR ASSERTIVE RESPONSE

"This program is not appropriate for my child. And P.L.94-142 requires an appropriate program for every child who needs special services. What my child needs is......".

6. "You're too emotional and too personally involved to really know what's best for your child. We are professionals. We know what's best."

YOUR ASSERTIVE RESPONSE

"You are the professionals, but I am the authority on my own child; I know him better than anyone else precisely because I am so personally involved."

7. "I'm sorry about your problem, but there's really nothing I can do about it."

YOUR ASSERTIVE RESPONSE

"Apparently you are not aware that P.L.94-142 requires you to provide the services child needs. Here's some material that explains what your responsibi ties are, and the penalties for any school district which does not comply."

8. "Do you expect us to change the whole school system just to accommodate your child?"

YOUR ASSERTIVE RESPONSE

"I expect you to obey the law and provide services for my child, required by P.L.94-142. Those services are.....".

5. Encouraging Networking Among Advocacy Groups

Once parents feel more familiar with their advocacy role, an effective way for a small parents' group to maximize limited resources is for its members to join the already-existing committees of various advocacy organizations, or community agencies that have an interest in severely disabled people. Some of these organizations have been mentioned previously (e.g., ARC, the Area Board for Developmental Disabilities, the Community Advisory Council, etc.). As representatives of the core parent group, the new parent members of these committees can be assured that their concerns will be heard. At the same time, joining these committees can be a powerful method of encouraging networking among groups.

4. TRAINING THAT CAN BE PROVIDED BY THE PARENT GROUP

The parent support group can provide two types of training for parents: 1) parents may want to learn about instructional objectives and strategies that they can implement with their child; 2) parents may want to participate in training activities that are designed to increase the general public's awareness and acceptance of severely disabled people. Both activities can be designed so that they lend themselves easily to a trainers of trainers model, which will make it possible for involved parents to help other parents acquire these same skills. As the name suggests, a trainer of trainers model is a procedure in which people who develop and conduct inservice education train others in ways to replicate, and/or modify the original training. The model that we suggest uses parents to help other parents acquire the appropriate new skills.

A. Training Using Instructional Objectives

Several programs and series of modules have been developed that teach parents of students with severe disabilities how to use systematic intructional techniques at home (Baker, 1976; Baldwin, Fredericks & Brodsky, 1973; Watson & Bassinger, 1976). These modules -- many of which are illustrated with drawings, graphs, charts and concrete examples -- are easily reproduced for handouts. They can also be converted into transparencies for overhead projection.[3]

The programs are most useful in small group sessions, where the basic principles behind operant training* can be introduced defined, and demonstrated. The programs concentrate on teaching procedures far more than content, because the authors couldn't present individualized objectives for children at all the possible skill levels and ages, in all the possible curriculum areas. The programs are based on the assumption that the classroom teacher and each parent will be working cooperatively to develop specific objectives and programs that parents can implement at home.

1. The ecological Inventory

It's important to note that the most recent innovation in special education for severely disabled people is a strategy

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* See the Glossary

known as the *ecological inventory* (or the *environmental inventory*)*, which was developed by a group of researchers at the University of Wisconsin, Madison. According to the people engaged in this work (Falvey, Brown, Lyon, Baumgart and Schroeder, 1980), the inventory refers to "actions undertaken to secure critical information about the school and community environments in which a severely handicapped student is currently functioning . . ." as well as those "in which he might function in the future." (Falvey, et al., 1980, p. 119). An ecological inventory identifies the critical behaviors that nondisabled people demonstrate in the relevant school and community environments, then assesses whether the severely disabled person in question now has any of these skills, the extent to which the skill will need to be adapted, etc. The unique feature of this approach is that it's a fully individualized educational strategy that's based on the idea that student learning objectives should be functional and directly related to the general environment (i.e., the neighborhood), and the subenvironments (e.g., the park, the streets, the playground, the store) that the students visit every day. An in-depth explanation of the ecological inventory process can be found in the *Inventory Process for Social Interaction* curriculum manual (Project REACH, 1983), and in the *Instructional Programming for the Severely Handicapped: A Functional Skills Approach* manual (Training and Resource Group, Special Education Resource Network of California, State Department of Education, 1982).

We encourage parent facilitators who plan to be involved in instructional training activities to study these manuals, and use inventory strategies for several reasons. First, ecological inventories, unlike traditional assessments, view parents or guardians as the key resuorce in designing a learning plan for their children. When the ecological inventory is used effectively, parents fully participate in their child's learning program by reporting on the current nonschool environments in which the child is functioning, as well as on future settings where parents hope or expect that the child will be able to perform. The focus is on *critical skills*, or those which will contribute to greater independence within present and future environments. In other words, unrelated "readiness skills" (e.g., stacking blocks or fitting pegs in a board), are replaced by activities that are appropriate to the student's chronological age. The new activities enable him or her to participate more fully in social activities with nondisabled peers and siblings, since the skills are based on what the student needs and wants to do (i.e., use the school cafeteria line, manipulate an adapted switch for use of a video game, etc.).

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* see the Glossary

2. <u>Training Guidelines</u>: (<u>First Phase</u>)

As we've mentioned, a group or workshop format can be a very effective way of introducing parents to a variety of concepts, such as:

- operant procedures/systematic instruction (i.e., behavior modification techniques used to teach students to acquire new skills)
- task analysis* (i.e., breaking a task down into a series of steps that can be learned one at a time)
- data collection (i.e., daily collection of progress information that might involve scoring a student's responses to a particular task)
- ecological inventory (see the preceding page)
- normalization/integration (i.e., the idea that education should be carried out in as normal a setting as possible)
- partial participation* (i.e., the idea that if a student can't go shopping alone, he or she can still participate by pushing the shopping cart, choosing certain items, etc.)
- critical skills/functional sequences (i.e., the idea that a child should be taught the skills her or she will need to be as independent as possible in later life)

When parents are greatly interested in receiving training that will help them apply instructional techniques in a systematic way at home, the facilitator should ask that the classroom teacher be involved from the outset. Although you can explain concepts without the teacher's being present, his or her input will ensure that the training is relevant to the specific students whose parents are being trained. If the teacher can't attend all the training, you might suggest that you and the teacher design initial training sessions together, and that the teacher become more actively involved as parents develop individualized inventories.

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* see the Glossary

If you, as the facilitator, do present broad concepts, such as operant procedures, to the parents, remember to supply concrete material to illustrate the concepts, such as:

- videotapes of students
- a demonstration using students
- films or slides
- overheads, handouts, and the like.

Two of the teachers working with Project REACH found that videotapes that depicted their students engaging in social interaction programs were a good vehicle for showing the rationale behind integration, the content of the children's program, and the methodology or teaching techniques being used. Through the use of the videotapes, parents were able to get a firsthand look at their children's interactions with regular education students of the same age. They also saw how age-appropriate games and toys could be used to encourage their child to interact fully or partially, and, they had a chance to watch what sort of instructional techniques were employed by the teacher. You can interweave definitions of terms and concepts with the videotape show by stopping the tape at critical points to discuss a concept or teaching strategy such as cue (stimulus), modeling, imitation, shaping, response, time delay, or reinforcement.

If you don't have access to equipment or staff for videotaping, one effective alternative is to invite a student or students from the severely disabled class to attend the workshop with the teacher. You and the teacher can plan to present specific instructional programs "live" in order to demonstrate important concepts to parents.

Films or slide shows (see the appendix for titles and addresses) are a third alternative. Although films won't deal specifically with the particular students in the class as videotapes will, they can still be helpful aids in illustrating concepts and key terms. One such film is Marc Gold's Try Another Way, which demonstrates how complex assembly tasks can be taught to severely retarded people using a nonverbal approach. (This film can be borrowed - at no charge - through Area Board V in the San Francisco Bay Area. It can be rented elsewhere through Film Productions, 128 E. 36th Street, Indianapolis, IN 46205).

Overhead projection or slides of children learning, accompanied by handouts that define key terms is another effective visual teaching technique. Parents can refer to the handouts later to review concepts and terms.

A particularly good slide show presentation which shows how critical functional skills (e.g., learning to make your bed, learning to dress yourself) can be taught at home and in the community is the "Individualized Critical Skills Model", available through the Training and Resource Group of the Special Education

Resource Network in the San Francisco Bay Area, (313 W. Winton Ave., Hayward, CA 94544). The Training and Resource Group slide presentation outlines the rationale behind "normalization", or the idea that severely disabled studens should be educated in as normal a setting as possible. This slide show also stresses the use of environmental inventory strategies.

If you want to make a slide presentation specific to the students whose parents you're involved with, you can refer to the Awareness and Inservice Manual (AIM) published by Project REACH (1983). The AIM has a section entitled "Using Audiovisual Materials to Aid Integration" which suggests some easy, cost-efficient ways to develop a show. You can begin by working out a schedule of important activities to photograph with the classroom teacher. You'll probably want to include integrated activities and environments, such as the playground, yard games, cafeteria, and hallway. Students undergoing training in the community (i.e., at the laundromat, the grocery store, etc.) will be good photographic subjects. You can also capture classroom training scenes, such as students learning communication, vocational, recreational, and daily living skills, or sequences combining several skills. You and the teacher can then view the slides, and develop your own script or tape to accompany the slide presentation.

This type of presentation would be the first segment of a parent group workshop in instructional training. The show can immediately be followed by questions, discussion, and review. At the next workshop, opportunities for parents to use these concepts to develop an inventory, and an instructional skills sequence can be provided.

3. The Second Phase of Training.

This phase can also be instituted using a group format, but if more than six parents are participating, it would be helpful to have two facilitators. You as the facilitator can lead one group, and ask the classroom teacher to lead a second small group.

During this phase, groups could be involved in the following activities:

- a home ecological inventory (see the following page)
- a community ecological inventory (see the following page)
- writing objectives for critical skills
- writing a task analysis and objectives
- devising a functional sequence design (i.e., a design that spells out the total sequence of an activity. For going to the bathroom, for example, the sequence would include pulling down pants, pulling up pants, toileting, washing and drying hands, etc.)
- designing a data collection plan

You should plan to spend at least one meeting on each of these topics and exercises. Parents can practice some techniques at the meetings, and can then carry out the full activity (e.g., a home or community inventory) between meetings.

The Home Ecological Inventory.

On the next page, you'll find a sample worksheet for parents. The form was developed by Kathleen Gee, a teacher of severely disabled students at a middle school that was part of Project REACH. She designed it to help parents identify the activities or the areas of family life in which their daughter or son currently participated, as well as those areas where parents hoped for increased participation.

Before filling out the form, small groups of parents working together with a facilitator can brainstorm and exchange notes about their daily routine, the ways their child participates, and the skills he or she would need to have to play a more active role in these activities and be more independent. This is an appropriate time for discussing and emphasizing "age-appropriateness" and "partial participation". To aid in these discussions, you might ask parents that following questions (after they've generated their list of home activities):

- did my nondisabled children participate in this activity when they were the same age as ____________? (Or, if they're younger, when will I expect them to participate in this activity?)
- at what age do I expect my children to begin having responsibility for specific chores around the house?
- what activity or job would I really like __________ to be able to help with? (e.g., his or her own dressing, bathing, grooming, eating, preparing food, washing dishes, setting table, putting toys away, etc.)
- what does ____________ like to do when he or she comes home from school? What do my other children like to do? Could these activities be adapted or changed so that _____________ could join in?
- what places in the neighborhood or community does _____________ go with family members? Where would I like to be able to take him or her? What would I need to do, and what skills will he or she need, in order to have this occur?

PARENT WORKSHEET

Time of the week:

What typically happens in the evening or on weekends or at home in our household (as a family or individuals)? List a rough time schedule:	How much does my son or daughter participate in those events?	What skills does he/she need to learn to participate even more in those activities?

Many more questions could be added to this list, and several will be suggested by parents discussing these issues. But since it may be difficult for parents of students with physical as well as mental disabilities to know how their children can engage partially in activities, you should point out examples of partial participation, such as learning to use an adapted switch for the TV, record player, or tape recorder; learning to play more independently, (given age-appropriate toys, or video games with adapted switches) etc. The examples you cite should be specific to the age of the student, and the severity of his or her disability.

On the next few pages, you will find more detailed sample forms that were filled out by the parents of a child we've called Adam. These forms, which were developed by the Training and Resource Group of the Special Education Resource Network in the San Francisco Bay Area, and adapted by the authors of Project REACH's _Inventory Process for Social Interaction_, provide spaces to list time, activity, present performance/level of assistance currently required, whether the activity is age-appropriate, and whether instruction in this area is a high priority. These inventories were developed for the cooperative use of parents and teachers, so that _critical skills_ needed by the student can be identified, placed in priority order, and included in the student's IEP.

However, all the following forms can also be utilized independently by parents, to aid them in advance planning for an IEP meeting, or in identifying areas for their own home instruction activities. After introduction and discussion of the forms in a small group setting, the facilitator might suggest that parents take the forms home with them, and complete their inventories before the next meeting. The facilitator might encourage parents to enlist the participation of siblings, grandparents, or any other household member, in the inventory process.

Community ecological inventory.

This second inventory may be a part of, or separate from, the home inventory. For some students, activities in community environments (e.g., stores, public transportation, laundromat, movie theater) may be a current goal, and parents will want to think of these activities as part of a daily or weekend schedule. For others, this type of participation may be a longer range goal. In either case, it's equally important that parents think about these environments and the skills and/or adaptations that their son or daughter will require to function effectively within them.

To help a parent fill out the forms, you, as the parent facilitator, or the classroom teacher, can first explain that the forms include the following:

1.	Student's Weekday Schedule	Everything the student does from the time he or she gets up in the morning until he or she goes to bed at night. This doesn't include school.
2.	Additional Weekday Schedule	Activities that don't occur every day of the week.
3.	Weekend Schedule	Everything the student does on the weekend.
4.	Summary of Interview	High priority activities that the student doesn't perform independently.
5.	Parent/Guardian Preference for Future Activities-Environments	High priority activities that the parent would like the student to perform in the future, categorized by the setting in which they take place.
6.	Initial Summary of Critical Activities/Skills	Summary of high priority activities. These are current and future activities the parent and teacher would like the student to learn.
7.	Tentative Goals, Activities and Environments	Tentative goals and possible activities - the student will be taught to attain these goals.

On the next page is background information on Adam -- the student we've used as an example so that parents can see the level of details they should put down in filling out the forms. The forms to be filled out follow.

Background on Adam

Student: Adam L.

Birth Date: 5/10/57

Age: 13 Sex: Male

Handicapping condition: Severe retardation - Down's syndrome

Mobility. Ambulatory

Toileting: Independent

Communication (receptive): Understands and can follow one-step directions.

Communication (expressive): Speaks in four to seven-word sentences; has articulation problems with final consonants.

Fine Motor: Difficulty in this area. Cannot rotate hand. Does not use fingers in opposition. Extremely weak grip. Does not tie shoes. Has trouble squeezing out a sponge.

Gross motor: Poor motor planning. Walks with awkward gait.

Socialization: Extremely social with adults. Avoids social interaction with peers.

Behavior: Tantrum behavior (kicking, hitting, yelling, destruction of property). Under control with behavior management program in classroom and community but not in the home.

Family: Lives with family - mother, father, and one younger sister.

School Placement: Adam is in a self-contained class within a regular school. There are ten other students with similar disabling conditions in his class. Adam receives services from a speech therapist, an adaptive P.E. instructor and an occupational therapist.

Weekday Schedule

The weekday schedule includes daily activities that occur on a typical day from the time the student gets up until he or she goes to bed at night. It does not include school time.

Going across from left to right the information collected includes:

1. Environment: This is the larger environment in which the activity occurs, e.g., home, community.
2. Sub-environment: This may be a room in the house or a specific store in the community where the activity takes place.
3. Activity: In this column you list the activity that takes place. An activity describes an outcome.
4. Approximate time: List the appropriate time the activity takes place. This may be important information in describing the student. The student may be able to dress independently if given one hour. It would be important to work on rate of dressing if this occurs.
5. Chronologically Age Appropriate? (yes or no): In this column you should note if the activity is age appropriate. Is it an activity that nondisabled people of the same age would engage in?
6. Present Performance/Level of Assistance Needed. In this column you will want to describe the level of independence at which the student currently performs this activity. What types of prompts do the parents use to help the student perform the activities? What adaptations does the student use to perform the activity?
7. Preference (high, medium, low): In this column you'll ask the parent to rank each activity as a high, medium, or low priority activity to be taught.
8. Comments: Any comments from parents or ideas you have about the activity that may be useful later can be written here.

WEEKDAY SCHEDULE - Worksheet 1

TRG

Student: Adam

Date: 9/26/83

Interviewer: Teacher

List information from the time the student gets up and goes to school to the time the student arrives home from school and goes to bed.

Environment	Teaching Area	Activity	Approx. Time	Age appropriate	Present Performance/Level of Assistance Needed	Preference	Comments
Home	Bedroom	Gets up	6:30	Yes	Mother calls him to get him up.		Suggested letting A. use alarm clock. Could be pre-set; he just needs to push button. Mom liked idea.
Home	Bathroom	Use toilet	6:40	Yes	Independent		
Home	Bedroom	Dress	6:45	No	Mother sets clothes out. A puts shirt on; doesn't button. A puts pants on; doesn't snap or zip. A puts shoes and socks on; doesn't tie shoes.	High	Mother admits A could do more but there isn't time in the morning. Easier to do it for him.
Home	Kitchen	Breakfast	7:00	No	Mother prepares and serves breakfast to A. A eats independently. Mother clears his dishes.	High	Mother agreed it would help her if A would participate at least in clearing his own dishes.
Home	Bathroom	Brush teeth, comb hair, wash hands/face	7:15	No	Mother brushes A's teeth. A combs his own hair. Mother washes his face and has to verbally prompt him to get his hands thoroughly wet and dry.	High	

STUDENT Adam

WEEKDAY SCHEDULE (cont'd) Page: 2

Env.	Teaching Area	Activity	Approx. Time	Age appropriate	Present Performance/Level of Assistance Needed	Preference	Comments
Home	Livingroom	Wait for bus	7:30	No	Mother gets his coat, folder, etc. ready for him. Boards school bus independently with belongings.	Medium	
REC. CENTER							
Home		Arrives home from Rec. Center	5:30		Puts school things down, takes coat off, brings notes to Mom. Does not hang	Medium	
Home	Kitchen	Snack	5:35	No	Tells mom he's hungry; says what he wants - Pepsi and chips usually. Mother prepares for him.	High	Talks with mom; tells her about school day.
Home	Backyard neighborhood	Leisure play with dogs, rides bike	5:45	Yes	Rides bike independently. Sometimes fights with neighborhood kids (name calling). Watches kids play basketball.	High	Lots of kids in neighborhood. Maybe Adam could learn to play basketball.
Home	Kitchen	Dinner	6:30		Adam does not participate in meal preparation table is set for him and food served. Eats independently Does not clean own dishes.	High	Mom would like him to set table, etc. Doesn't know how to teach it.

STUDENT Adam

WEEKDAY SCHEDULE (cont'd)

Page: 3

Env.	Teaching Area	Activity	Approx. Time	Age appropriate	Present Performance/Level of Assistance Needed	preference	Comments
Home	Livingroom and bedroom	Leisure	7:00	No	Adam has nothing to do so he annoys his sister and mother. Doesn't like T.V. Sometimes destroys sister's things and tantrums.	High	
Home	Bathroom	Bath	7:30	No	Father gives Adam bath. He does not wash self.	High	Mother was giving bath - felt A. was too old - Father has started doing this now.
Home	Bedroom	Dress	8:00	Yes	Dresses for bed independently	Low	
Home	Livingroom	Leisure	8 :45	No	Same problem as above. Adam cannot handle free time.	High	
Home	Bedroom	Bed	9:00		Goes to bed with verbal cue.	Low	

ADDITIONAL WEEKDAY ACTIVITIES - Worksheet 2

Student: Adam

Interviewer: Teacher

Date: 9/26/83

List any activities that occur throughout the week (M-F), but not on a daily basis.

Envir.	Teaching Area	Activity	Approx. Time	Age appro-priate	Present Performance/Level of Assistance Needed	Pref-erence	Comments
Com-munity	Grocery store	Shopping	5:30	No	Picks out some familiar items and things he wants. Runs into people when pushes cart. Gets loud waiting in line and if mom won't buy things he wants. Mother lets him pay if she's buying a few things.	High	Mother very concerned about Adam's behavior in store. Has had to take him out.
Com-munity	7-Eleven	Buy drink and news-paper	5:30	No	Adam tells mother what he wants. She asks for drink for him. She pays. Mother buys newspaper	High	Mom says she would like Adam to do these things independently.
Com-munity	Visit with friends, relatives		5:30	No	Sits with adults. Does not entertain self. Wants adult attention.	High	Always wants adult atten-tion. Parents would like him to be able to enter-tain himself, look at books or something.
Home	Kitchen	Make bag lunch for Friday		No	Tells mom what he wants. She makes it.	High	Would like him to learn to make own lunch.

Weekend Schedule

On the Weekend Schedule you will want to find out everything the student does on the weekend, and particularly those activities that do not occur on weekdays because of school. Weekend activities are often lacking with severely disabled students because of lack of social skills, and competence in independent and group recreation and leisure activities.

TRG

WEEKEND SCHEDULE - Worksheet 3

Student: Adam

Interviewer: Teacher

Date: 9/26/83

List weekend activities that occur regularly

Envir.	Teaching Area	Activity	Approx. Time	Age appropriate	Present Performance/Level of Assistance Needed	Preference	Comments
Home	Bedroom	Get up	8:00	Yes	Independent	Low	
Home	Bedroom	Dress		No	See weekday schedule	High	
Home	Kitchen	Breakfast	9:00	No	See weekday	High	
Community	Community	Leisure activities		Yes	Rides bike, rides motorcycle with dad, goes fishing, goes hunting	Low	
Community	Laundromat	Laundry		No	Adam helps mother put clothes in washer and dryer, pulls clothes out. Does this with verbal cues.	Medium	Could get change, fold clothes, sort clothes.
Community	Restaurant	Order, eat		No	Mother orders what he wants, carries it to table for him.	High	A makes a fuss when he finishes eating. Mother has to leave sometimes.

Preliminary Summary of Priority Activities

This work sheet will help you to summarize the information collected from the Weekday Schedule, Additional Weekday Activities and Weekend Schedule work sheets. To fill it out, go through the worksheets and list activities which parents/guardians have indicated as high priority activities for instruction. As you do this with the parent/guardian they may want to add or delete activities.

PRELIMINARY SUMMARY OF PRIORITY ACTIVITIES

TRG
1/82

Student: Adam

Interviewer: Teacher

Date: 9/26/83

1. Summarize activities from Worksheets 1, 2, and 3 that parents have indicated as HIGH preference activities for instruction. Are they still high priority? Do activities need to be added or deleted?

ACTIVITIES: PRESENT ENVIRONMENTS
(Work Sheets 1-3)

High Pref. Activity	Notes	High Pref. Activity	Notes
Independent leisure		Button shirt, tie shoes, zip pants	
Basketball		Brush teeth	
Indoor games with peers		Wash dry hands and fac	
Domestic chores		Order, eat [illegible] restaurant	
Simple meal preparation		Entertain self indoor activities	
Shop for familiar items			
Get drink 7-11 with peer or sister			
Laundromat			
Telephone friends			

Parent Preferences:
Future Activities - Environments

Training for severely disabled students should always be future oriented. Teachers need to train skills which will allow for greater participation in current and future environments. Teachers should always be thinking at least three years ahead for their students. Remember, it takes longer to train severely disabled students. A crucial element in identifying and prioritizing activities to be taught is whether the student will be able to continue to expand on and use that activity in future environments.

This worksheet has been divided into the following five domains:

1. Domestic are any activities which occur in the home.
2. Recreational/Leisure are activities which the student may engage in by himself or with others, such as entertainment during leisure time.
3. General Community are activities which take place in the community, such as shopping, eating at restaurants, using other public facilities.
4. Interaction with Nondisabled are activities which may occur in any of the other four domains which involve some type of interaction with nondisabled people.
5. Vocational are activities which involve all types of work skills from being able to complete a task, to following directions, to actually carrying out a real job.

When filling this work sheet out with the parents, ask them to think about what they would like for their student to be doing three years from now in each of the following areas. You can refer to the community and neighborhood inventories when identifying where these activities could take place.

After listing the activities and environments, have parents rank high, medium, or low preference for each activity.

Parent Preferences:
Future Activities - Environments

TRG

Student: Adam

Date: 9/26/83

Interviewer: Teacher

1. Have parents list the activities that they'd like their child to be doing three years from now above the dotted line. Where would these activities take place? (Use Community/Neighborhood Inventory Information -- and list below the dotted line).

2. After completing the list, have parents rank high, middle or low preference for each activity. Put the rating in the column next to the activity.

Domestic	Pref H,M,L	Recreational/ Leisure	Pref H,M,L	General Community	Pref H,M,L	Interaction with Nondisabled	Pref H,M,L	Vocational	Pref H,M,L
Prepare simple meal	H	Basketball	H	Shopping	H	Basketball	H	Functional job training	H
Home School		Neighborhood School		Community		Neighborhood School		School Community Home	
Dress independently	H	Bowling	M	Restaurant (fast food)	H	7-Eleven with peer	H		
Home School		Community		Community		Community			
Wash independently	H	Entertain self	H	Library	M				
Home School		Home School Community		Community					

Parent Preferences:
Future Activities - Environments (continued)

TRG

Student: Adam

Date: 9/26/83

Interviewer: Teacher

Domestic	Pref H,M,L	Recreational/ Leisure	Pref H,M,L	General Community	Pref H,M,L	Interaction with Nondisabled	Pref H,M,L	Vocational	Pref H,M,L
Domestic Chores	H	Indoor game with peer	H	Ride bus	M				
Home School		Home School		Community					
ch teeth	M			Laundromat	M				
me				Community Home					

B. Community Training Activities

Parents can be very effective at increasing the community's acceptance of severely disabled children and teenagers (Freagon and Wheeler, 1982). One possible role parents can play is to provide information to community groups such as school boards, civic groups and organizations (e.g., PTAs, Kiwanis, Rotary Club, Jaycees, Women's Clubs, Business and Professional Women's Associations), and church groups, the police and fire departments, and municipal transportation companies (Freagon and Wheeler, 1982). In addition, parents can make presentations to certain generic service providers (i.e., agencies that provide general services to the public) who may be able to offer activities to people with severe disabilities -- e.g., the YM/YWCA, Boy/Girl Scouts, Recreation Departments, etc.

Just as parents need to increase their information level before being effective advocates, the knowledge base of community organizations will also have to be increased before they accept severely disabled people.

Among the organizations parents will want to reach are:

- the PTA
- the School Board
- recreation programs
- municipal services
- business & civic groups
- church groups
- neighborhood associations

1. The PTA: An Appropriate Starting Point

Because the PTA will be highly influential in the decision to accept or impede the integration of classes for severely disabled students at regular schools, it is important to consider that parents of regular education students will probably have questions and concerns about how much integration will occur, and what the benefits will be for their children. These parents' fears, misinformation, or lack of information can be addressed through presentations arranged and led by your parent support group. The latter can schedule the presentations either before or immediately after the classes for severely disabled students begin at the regular school.

The First PTA meeting.

In order to establish a good working relationship with the PTA, the parent support group and teacher(s) of the severely disabled students will need to be in close contact with the principal of the school, and its PTA officers from the beginning of the

7?

school year. The facilitator or teacher might suggest to the principal that he or she send out a letter to all parents announcing the new integrated program, and explaining the purpose and goals of integration (see the example on the next page). Since the principal as well may be new to integration, you or the teacher could draft an outline of key points, to be edited by the principal before sending it out. One principal we worked with chose instead to announce the new program in the biweekly news bulletin that was sent home to the parents of all the students. Whether a letter or other means of announcement is used, the news should go out before the first "Open School Night" or PTA meeting.

The exact format of the presentation you make at this first meeting will depend on the structure of the school's PTA. At REACH sites, we've presented information in a variety of ways, ranging from making brief oral remarks to using narrated slide or video presentations, disability simulation exercises, or "Awareness Learning Stations" (see the AIM, Project REACH, 1983). We've also arranged visits for parents of regular education students to the special classrooms. You can consult with the principal and PTA president in advance of the first PTA meeting to decide which presentation is most appropriate.

When the parent support group makes an initial presentation to the PTA, at least two people should be involved: the classroom teacher, and a parent or facilitator-parent. The teacher may want to briefly describe the curriculum for severely disabled students, and the activities or environments where integration will occur (e.g., the cafeteria, assemblies, hallways, field trips, gym, playground, music class). The teacher may also want to take this opportunity to mention that a "peer tutor" or "special friends" program will be initiated. After describing the responsibilities and benefits inherent in such a program, the teacher can let parents know that student volunteers are needed. We found that parents were quite successful at recruiting their children to volunteer for the peer tutor program.

Ideally, the presenter will accompany his or her remarks with slides or video. Or, if time and/or resources prevent this, the parents attending this PTA meeting should be encouraged to see the goals and advantages of integration "live" by visiting the classroom of severely disabled students.

If the classroom teacher isn't available, two parents of the students in the newly integrated class may be just as effective in presenting these advantages to a PTA group. For one, parents have high credibility with other parents. Secondly, a parent is likely to describe the purpose of integration in everyday terms understandable to those who are unfamiliar with special education. (In short, with a minimum of jargon!) Hearing that a parent of a severely disabled child wants the child to have the chance to learn from friends her age who are not disabled may mean more to the average PTA member than hearing about structured social programs to increase interaction.

Jose Ortega School
400 Sargent Street
San Francisco, CA 94132
587-7529

February 20, 1981

Dear Parents/Guardians:

Jose Ortega School is starting a pre-school class for severely handicapped children aged 3 to 5. This week, we will be talking to your child's class about these new students: What it's like to be handicapped, how people become handicapped, and about ways to act with handicapped people.

The new class is being sponsored by the U. S. Office of Special Education and San Francisco State University, in cooperation with the San Francisco Unified School District. Jose Ortega is part of a 3-year plan aimed at helping severely handicapped children sttend school.with non-handicapped children. The reasons for this are, first, that every child has to be educated in as normal a setting as possible, and second, that all children will benefit from learning to appreciate differences among people. Our pre-schoolers have physical handicaps (some use wheelchairs), hearing and sight problems, as sell as varying degrees of mental retardation. They will have their own classroom (Room 4) and teacher, but they will be joining your child on the playground, in the halls and lunchroom. Children from the new class may also share art, music, or P.E. activities with the Kindergarten and First Grade rooms. We are working now to prepare your child and his/her class to understand and accept the new students.

We expect that your child will have questions about the new pre-school children. For example, children who meet handicapped persons for the first time often wonder, "Does it hurt?" We answer this by saying, "Being handicapped doesn't hurt - it's the way people sometimes act towards handicapped people that hurts." Children also ask, "Can I catch what he's got?" This can be answered by saying, "no-if you have a cold or something that's catching, you stay home; handicapped kids do that too." These are just two examples of the worries children have expressed in the past. If your child has questions you can't answer, or if you would like to talk with us about this new program, please contact the school.

We appreciate your help in our effort to make sure that the handicapped pre-schoolers get a warm welcome at our school.

Sincerely,

Jon Lucero

Jon Lucero, Principal

cc: Mr. H. Marshall, Area III Superintendent
Mrs. M. Chinn, Area III Program Manager

If this initial PTA meeting affords only the opportunity for brief oral remarks, the facilitator, parents, and teacher should request a meeting with PTA officers to plan a future, more extensive presentation. REACH also strongly recommends that the parents of the severely disabled students become members of the PTA, which usually requires only a nominal dues fee.

The Second PTA Meeting.

Once the second in-depth presentation is scheduled, the facilitator can emphasize to parents of the severely disabled students that more of their participation will be needed in planning their own training. Training sessions for the parents can be designed so that the information and hands-on experience gained will be equally useful for presentations to other target groups. Parents can then choose the type of presentation that they would be most comfortable giving.

One good place to start is with a media presentation. As noted earlier, numerous films are available that cover normalization issues as well as curriculum for severely disabled students. Several of these are listed in the *Resources* section of the Appendix. In addition, Project REACH's *AIM* contains a bibliography of books, films, and slide shows that are designed for increasing able bodied peoples' knowledge about disabled people. The parent group can review a sample of these before the planned presentation, and decide which film best represents their children and their capabilities, which film presents disabled people in the most positive light, and so forth. We'd like to stress again that the ideal media are videotapes or slides of the actual students themselves, engaging in basic skills programs within the school and surrounding community.

If parents decide that existing films are inappropriate, they may want to volunteer to put together their own slide presentation with the facilitator and/or classroom teacher. This would give them the opportunity to show classroom situations that can lend themselves to a *peer tutoring* or *special friends* format (See the *AIM*, Project REACH, 1983, for a full description of the peer tutoring/special friends program).

Practice sessions will be needed so that the parents of the severely disabled students can experiment with responses to questions from the parents of regular education students. Sample questions that have been asked at REACH presentations include:

- What types of things are your children/students learning?
- Aren't the facilities better in a segregated/special school?
- What are the causes of your children's handicaps?
- Why would you want to subject these children to possible teasing, ridicule, etc.?

- How many staff are with the class? What is their training?
- What activities will you be integrating? Will special staff be with these students for these activities?
- How does peer tutoring work?
- What are the benefits for my child?

The parent group should discuss their answers to these and other questions, reach a consensus on the answer(s), and decide who will be responsible for specific sections of the presentation.

Another type of presentation that can have a dramatic impact on the audience is the <u>disability simulation</u> (see Appendix C). These "simulations" are exercises that children and adults carry out at several learning stations to feel what it's like to be disabled, and thus increase their sensitivity to difficulties encountered by the disabled person. A key feature of these learning stations is being able to experience compensatory or adaptive techniques that people with the disability use to overcome various problems (e.g., plates with curved edges to aid in picking up food, an adapted spoon, a communication board that has photos or line drawings that a disabled person can point to to show what he wants to communicate). Like the <u>KIDS Project</u> (at the Center for Independent Living in Berkeley, California), it is REACH's goal to leave parents, students, and regular education professionals with a positive impression of disabled people.

REACH learning stations include:

1) Mental Retardation
2) Deafness
3) Blindness
4) Physical Handicaps
5) Alternative Communication Systems
6) Adaptive Equipment/Prosthetics

Three to four of these stations can be presented concurrently to a group. REACH decides which stations to present, based on the disabilities of the severely disabled students at the school. Stations generally run seven to ten minutes each, and the group is divided, and rotates among them. A large group discussion period follows after the simulations.

One example of how to use a learning station to present the positive aspects of disability involves giving a puzzle to those who participate in the mental retardation learning station. The five-piece puzzle was developed by the Headstart program (<u>Headstart - Mainstreaming in Headstart: Training Strategies</u>, NYU School of Continuing Education, Office of Community Services, Region 2). Because the puzzle is frameless and contains no cues as to its complete shape, it's extremely difficult to put together. After handing it out, the person running the station states a brief time limit and "harasses" the group while they're attempting to assemble the puzzle. At the end of the alotted time period, group members are asked how they felt when they couldn't solve the puzzle. Feelings of frustration and incompetence are explored and compared to the feelings a mentally retarded individual might experience when confronted with an apparently easy task that he or she cannot complete.

After group members discuss their feelings, they are given the same puzzle, but this time it has a picture of how it will look when it's complete. This additional cue simplifies the task, and the group successfully completes the puzzle. The leader then points out that given similar additional cues, or a breakdown of the task, people with mental retardation can also learn. Some examples (such as the use of recipes that are a combination of pictures and words) can be discussed at this time.

With the instruction sheets and one or two modeling sessions, followed by a practice period, parents can easily assume the role of station leaders. When the parents conduct a PTA workshop using the learning stations, four parents and the facilitator should plan to be present. The workshop can take place either in a few classrooms, in a cafeteria or in a gym. If more than 25 people attend the presentation, you'll need to schedule the sessions so that no more than six or seven adults are present at any one station at the same time. One way to handle the logistics is to present a 40 minute film or slide show in one classroom while learning stations are conducted in another location. Since each session will take 40 minutes, groups can switch places when they've seen the film, or gone through the learning stations.

Parents trained to present learning stations will find it relatively easy to train other parents in these skills. REACH has found that most station leaders enjoy the experience, and are further motivated by the positive feedback they receive from those attending.

Trainer of Trainers Model

You can begin recruiting parents to act as workshop leaders and trainers-of-trainers as soon as you know that they're concerned with and interested in integrating their severely disabled children with regular education children. Once those parents who volunteer to be trainers receive their training and participate in PTA workshops, there are several other ways for them to utilize their new skills. The local school may want its student body to receive awareness training, but may lack the resources for carrying it out. The parents who've received training can then volunteer to conduct a series of workshops for regular education students at the interested school (or at any school within the district that has severely disabled students). The group can also train other parents to be volunteer trainers.

Next, the group will want to generate a list of community groups and service providers who can benefit from awareness training. Different groups of parents will obviously have different priorities when it comes to deciding who should be trained. Parents of teenaged students may want to focus on business groups or companies that may have future vocational opportunities for severely disabled adults. Parents of younger students, on the other hand, might be more interested in focusing on recreational programs that could be accepting severely disabled students.

One or two parents should take responsibility for contacting these groups and scheduling presentations. In doing so, the parent group should reach agreement on the objectives of the presentation. For example, [illegible] you want the Girl Scouts to accept one or more severely disabled students into age-appropriate troops this year? Do you want the local recreation department to integrate severely disabled children into existing programs? How will you do a followup on the local sheltered workshop to determine whether severely disabled adults are moving from day activity programs into more competitive work placements?

These questions, and the objectives decided upon by the group, are prerequisites to meaningful community awareness training. Without them, presentations and workshops will be little more than "one-shot deals" with minimal impact. By developing an action plan, such as the one discussed earlier in the section on advocacy (see Chapter 3), you'll have the maximum effect.

One further way to add impact to your action plan is to network with other established groups who have similar objectives. Once your group has its "traveling show" and action plan organized, these community contacts can be very helpful in opening doors. In the San Francisco Bay Area, groups such as the Center for Independent Living, the Association for Retarded Citizens, the Developmental Disabilities Council, and San Francisco State University's Special Education Department, among other groups, are extremely proficient at networking and identifying potential advocates within the community. To make contact with similar groups in your area, a parent can call one of these agencies, explain the action plan that the parent group is carrying out and ask how the parent group can coordinate its activities with the agency, whether there are other groups outside the schools that would be receptive to awareness workshops, and whether anyone at that particular agency would like to be trained to provide workshops.

When you begin networking, remember, too, that the parents in the group will probably represent a wealth of contacts and resources. Some parents may belong to civic groups or neighborhood associations; others may be employed by municipal service organizations. These contacts should be explored when the group decides on its goals and action plan. Still other parents may have nondisabled children currently involved in the Boy Scouts or the local day camp. If these nondisabled children want their siblings to join their Boy Scout or Girl Scout troop, the children can ask the troop leader whether their disabled brother or sister can join. This is often much more effective than calling up all the troops in the area, and then suggesting that they accept severely disabled children.

On the following pages, we've presented training outlines, objectives and a sample of the handouts that REACH used during a series of spring, 1983, training sessions. The sessions were designed to teach parents how to support the integration of their severely disabled children into regular schools. Five parents volunteered for a day training group, and five for an evening training group. These parents received a stipend at the completion of the training sessions, in exchange for committing themselves to conduct at last f r awareness training sessions during the 1983-1984 school year. The parents stated that it was a high priority for them to train oth parents of special and regular education students to become trainers during this time period, too, in order to ensure that the program would continue, and become a generative training model. The REACH parents who volunteered for this program represented four project schools, the Community Advisory Council for Special Education, and the Association for Retarded Citizens of San Francisco (since the parents were members of these committees).

REACH Parent Training Plans

Trainer: The Parent Group Facilitator

Commitment:

- three to four three-hour sessions
- eight to 12 parents
- Contracts of commitment to train others

First session: Background Training in Normalization (see the following pages for a more detailed plan)

Time: two-three hours

A. (40 min) Definition, rationale and components of normalization/integration (the format can come from Project Co-Action. See the Appendix, for an address and phone number); discussion

B. (10 min) Integrated vs. traditional model: history/PL 94-142/the pros of integration

C. (20 min) Functional curriculum - critical skills to ensure success in future environments; discussion

D. (30 min) Overview of REACH activities in schools and inservice - show REACH videos (See the Appendix for REACH's address)

E. Plans of next three sessions -- each parent signs up for two awareness stations

Second Session: Training for awareness stations

Time: two-three hours

A. (30 min) Modeling of four stations (Mental Retardation, Physical Handicap, Blindness, Deafness/Communiction) by parent coordinator. Two-three parents at each station

B. (40 min) Practice of stations by parent trainers -- 20 min. for each participant

C. (60 min) One parent from each group does station for remaining three groups; set dates for reaching target groups; get all parents' schedules. Have group elect/choose parent as coordinator

D. (20 min) Discussion, handouts of instruction, plans

Third Session: Training on second station

Time: two-three hours

Same format as second session, but each parent has a new station

Final Session:
Time: two and one half-three hours (if possible)

A. (one hr) View two-three short films for use in schools and with groups (use ones available from REACH or Area Board V - see Appendix for addresses), handout: catalog

B. (one hr) Discuss possible target groups Prioritize groups - e.g., 1) schools with immediate need, 2) YMCA, Parks & Recreation Dept., 3) neighborhood associations, civic groups, 4) vocational service providers. Set dates for reaching target groups. Get all parents' schedules. Have group elect/choose parent as coordinator.

C. (30 min) Social - wine/cheese or desserts

First Session of REACH Parent Training to Support Integration

1. Introductions: everyone introduces self

2. (10 min) Explain details of training:

   - number and times of sessions
   - contracts/commitment
   - stipend after training completed (if funds are available for stipends)
   - general content to be covered
   - goals for training (i.e., what we want to see happen in regard to integration)/the groups we might train:

     regular education kids, staff, PTAs, agencies, community associations, recreational program staff, vocational staff, business groups

3. (20 min) Rationale for Normalization/Integration

   a) Go over definition of normalization (See the "Three Key Phrases" - handout #1 (which follows) - discuss each phrase. Normalization is the basis or philosophy for integration -- then look at Handout #2: Traditional vs. Normalization - a comparison. Read together. Ask for additions, reactions.

   b) (5 min) We have rights and the ability to lead a "normal life" -- we may take this for granted. What if we had to give up ay of these rights? Handout #3: Basic Human Rights. Ask each to note which would be the toughest to give up. Then ask how the person would feel if he or she had no control and had to give this up.

   c) (5 min) Ask group: What are other reasons for normalization/integration? Note these.

4. Benefits of integration - one aspect of normalization

   a) (5 min) Ask first for participants to define integration -- write answers on chartpaper

   b) (15 min) Present flip chart entitled "Rationale for Integration": Point/Counterpoint ___ Handout #4

   c) (15 min) Present Benefits of Integration, Handout #5 -- discuss each, add to, see if everyone agrees

d) (15 min) Discuss Functional Curriculum handout - Best setting is integrated one. Developmental curriculum (as opposed to functional curriculum) can be inappropriate for age; stresses non-critical skills. Functional curriculum needed to ensure success in future integrated environments. Therefore curriculum should be decided at least in part by parents. Questions, discussion.

e) ([illegible] min) Use REACH videos on integration: (see Appen- [illegible] REACH's address): Ortega, Presidio

f) [illegible] -- make plans for next week; choose stations.

Ann T. Halvorsen, Project REACH, March 1983

Three key phrases: NORMALIZATION, CRITICAL SKILLS CURRICULUM, PARTIAL PARTICIPATION

NORMALIZATION: participation in normal life experiences to the greatest extent possible, at levels that are age-appropriate.

CRITICAL SKILLS: looking at various environments in which the student functions and determining how the student can be more independent in those environments.

PARTIAL PARTICIPATION: when a student cannot participate independently in an activity, this means allowing or teaching him or her to independently perform as much of the activity as possible. For example: grocery shopping - carrying the basket and the list is partially participating (vs. going to the store independently).

Students in their teens need to have certain areas of their curriculum stressed. The traditional developmental assessments (such as the Denver Developmental Checklist) are often inappropriate by this time. Assessment scales often list isolated, tiny skills that are based on normal development. Therefore, a compromise between the developmental model and the critical skill model is required. (See the References, p. 164: Sailor and Guess, 1983)

Areas of curriculum that are most important:

COMMUNICATION SKILLS

VOCATIONAL SKILLS

INDEPENDENT LIVING
SELF-HELP SKILLS

LEISURE SKILLS

SOCIAL SKILLS

COMMUNITY SKILLS

All of the above areas are related to each other. For example: In order to hold a job in the community you need to be completely independent at toileting or have an arrangement with an attendant; putting your clothes away independently is an independent living skill; however, it is also a vocational skill because it requires independent work behavior.

K. Gee, 1982

Handout #2

TRADITIONAL VIEWS/NORMALIZATION

COMPARISON

TRADITIONAL VIEW	NORMALIZATION
Person seen as: 1. sub-human 2. object of dread 3. object of pity 4. eternal child 5. sick person 6. holy innocent	Person seen as: 1. human being 2. citizen 3. developing person
ENVIRONMENT Put away from the rest of society. The most restrictive environment is preferred.	**ENVIRONMENT** Person has the right to live with natural family. Family should be provided with the support necessary to make that possible. The least restrictive environment is preferred.
SEGREGATION Person should remain with their "own kind" they will be happier that way.	**INTEGRATION** Person has the right to be integrated into society.
RESPECT OVER PROTECTION Expectations low - person not allowed to make decisions.	**RESPECT DIGNITY OF RISK** You cannot grow or learn unless you take risks. Person allowed to make their own decisions.

ABSENCE OF AGE-APPROPRIATE EXPERIENCES dress boys/girls school bus childlike recreation children/adults chaperoned/large groups	PRESENCE OF APPROPRIATE EXPERIENCES Every person has the right to experience a normal life cycle. children-family setting school adolescence adult old age
SEXUALITY-REPRESSION repress it sterilization no marriage no intimate relationships	SEXUALITY SELF-EXPRESSION meaningful relationships with the opposite sex should be expected and encouraged
MEDICAL MODEL Person seen as sick, dependent on doctors for assistance. "hospital"	DEVELOPMENTAL MODEL Person seen as an individual with unlimited potential for growth and change. Seen as "like" the rest of society rather than unlike.
LABELS Words express the devaluation of the individual: they, them, their, those, retard, CP, MR, patient, my mongoloid son. The deviant image is reinforced by words.	RESPECT IN WORDS People first ... not their disability. "she has CP", not "she is CP
PHILOSOPHY person is deviant person is devalued less than human no rights unable to learn	PHILOSOPHY person has special needs same rights as peers able to learn

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Adapted from design by Gail Frazier West, Parent Advocacy Counselor, Sonoma County Citizens Advocacy, Inc., 1978.

Handout #3

IC HUMAN RIGHTS

☐ 1. The right to normal economic standards:

The right to make a living; the right to a financial standard of living that is considered normal; the right to have your own checking and savings account; the right to take advantage of compensatory economic security means such as child allowances, old age pensions and minimum wage regualtions; the right to have money and decide how to spend it on personal luxuries or necessities.

☐ 2. The right to a range of choices, to decide and choose for oneself:

The right to have your wishes and desires respected and considered; to have the freedom to decide where you want to live, what kind of job you would like to have and can best perform; the right to choose your hobbies and leisure time experiences.

☐ 3. The right to live in normal housing:

The right to live in a normal neighborhood in a normal location and normal size home and not be isolated unless you choose to be.

☐ 4. The right to live and experience a world made of two sexes:

The right as a child and adult to develop relationship with members of the opposite sex; to have both male and female friends; the right to fall in love and to marry or couple.

☐ 5. The right to normal developmental experiences and a normal routine of life:

The right to experience a full childhood which is rich in warmth of atmosphere and sensory stimulation. The right to experience normal development phases such as education, summer camp for children, friends and activities in adolescence; the right to experience work and responsibilities in adulthood; in old age, the right to enjoy the wisdom of experience.

☐ 6. The right to a normal rhythm of the year:

The right to find time to put changes into your life situation; the right to a vacation and the leisure activities that come with the seasonal changes of the year such as different food, cultural events, sports, summer camp as a child.

☐ 7. The right to a normal rhythm of the day:

The right to a normal routine, to get up in the morning, get dressed, leave the house for school, work or recreation, have activities to which you look forward.

Handout #4

Rationale for Integration: Point/Counterpoint*

ARGUMENT AGAINST	RESPONSE
1. Related service delivery (physical therapy, occupational therapy, speech therapy) is more eficient in segregated settings.	1. Administrative convenience is not a reason to segregate students. Must look at who benefits from each model. Integration is more efficient for the students.
2. Segretated schools have been modified so that there are no architectural barriers.	2. Barriers are no longer a legal basis for segregation. (1973 Rehab. Act, Section 504). Also, some barriers can contribute to learning.
3. It is easier for students with severe disabilities to make friends with others who are functioning at similar levels in segregated, "homogenous" schools.	3. Students with severe disabilities need to be able to function in heterogeneous (diverse) social environments with all kinds of people throughout their lives. Therefore, they need an integrated school experience.
4. The social-emotional growth of nondisabled students may be negatively affected by interactions with students who have severe	4. Reseach and experience show that able-bodied students benefit from those interactions in: • positive attitude change and increased acceptance of individual differences, • new responsibility and skill development, • reciprocal friendships
5. The presence of students with severe disabilities may interfere with the quality of education for nondisabled students	5. Interactions do not need to interfere with ongoing regular education programs, but rather to enhance them. Advantages result for nondisabled and disabled students, regular and special educators, and parents: • Severely disabled students have a variety of environments in which to learn and practice skills, • More individualization may result for nondisabled students • Special Education teacher can consult with regular education teacher to develop individual plans, • Special education teacher gains from opportunities to observe activities of nondisabled age-peers of the severely disabled students. • Parents and teachers of students with severe disabilities are no longer isolated • Regular education students may receive credit (through "Unified Arts" or "Inside Work Experience") for peer tutoring.

(See Benefits handout for additional items)

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* Brown et al., 1979

Ann T. Halvorsen, Project REACH

Parent Training
REACH 1983

Handout #5

Benefits of Integration

For:

Students with Severe Disabilities

1. Age-appropriate role models are present during social and nonacademic activities.

2. Positive behavior changes occur in students with disabilities as a result of struc-contact with nondisabled friends.

3. Increased motivation in learning activities occurs when students are working with an nondisabled friend or "peer tutor". One-to-one and group learning situations are possible.

4. Participation in school activities appropriate for his or her age, e.g., recess, lunch, assemblies, field trips, music, art, gym, community (cooking, shopping), dances, etc.

5. Special friendships between nondisabled disabled may extend beyond school to extracurricular activities.

6. Students with disabilities are exposed to expectations of the everyday world, rather than being sheltered from these.

7. Parents can become part of the school's PTA and may have more contact with parents of nondisabled students than they had previously.

8. Opportunity for integrated therapy model: physical, occupational, and speech therapists consult with teachers and help them to carry out same therapy programs themselves with the students. This leads to more therapy hours during class time, and greater learning for the student.

9. Other:

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____

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For:

Nondisabled Students

1. Increased familiarity leading to positive attitude change and acceptance of students with disabilities or other differences.

2. Increased understanding of the abilities or strengths of students with disabilities through contact with them in peer tutoring, social activities, etc.

3. Some nondisabled students have shown improved behavior as a result of working with severely disabled students in peer tutoring programs.

4. Regular education students in middle and high schools can receive credit for volunteering to work with disabled friends through Unified Arts and "Inside Work Experience" programs (i.e., the students receive elective course credit for working with disabled peers, just as they would if they took metal shop courses, etc.).

5. Special education teachers may be able to consult with, and help regular education the teachers with any of their students who have learning or behavior problems.

6. Collecting data on learning and learning to make graphs of these data can supplement a regular education student's math skills.

7. Regular education students are the community leaders and parents of the future, and those who have learned to appreciate similarities and differences among people will be more equipped to deal with the world as adults. This will lead to less segregation and more opportunities for their disabled peers as well.

8. Students with disabled people in their families will acquire greater understanding of these family members.

9. Other:

____

____

REACH Parent Training to Support Integration

Objectives for the Training

Session #1

1. The participants will be able to explain the rationale for integration and normalization of students with severe disabilities.

2. The participants will be able to explain at least two benefits of integration for severely handicapped students and at least two benefits for nondisabled (regular education) students.

3. The participants will be able to present basic information about the components of the functional critical skills curriculum for students with severe disabilities.

4. The participants will be able to identify the characteristics of successful school integration, including the types of activities where integration can occur.

Sessions #2 and #3, Learning Stations:

1. The participants will be able to identify the materials needed for two disability simulations (out of five: vision, communication, locomotion, mental retardation, prosthetics).

2. The participants will be able to lead two learning stations (i.e., disability simulations).

3. The participants will be able to answer questions, and lead a short discussion after conducting a learning station.

4. The participants will be able to train another person to lead a disability simulation.

Sessions #4 and #5, Media:

1. The participants will be able to identify films that are appropriate for a particular age group of regular education students and/or nondisabled adults.

2. The participants will be able to lead a discussion following the film.

3. The participants will generate and prioritize a list of groups and/or schools to target for awareness training.

4. The participants will elect a coordinator from their group to handle scheduling and contacts.

5. MAXIMIZING THE PARTICIPATION OF EXISTING AGENCIES AND SERVICE PROVIDERS

Asking parents to become members of important committees of local agencies is an extremely effective way of ensuring that a parent group (or groups) is kept informed of new policies and actions taken by service providers and advocacy groups. It's also a good way to stay abreast of pending legislation. Some of the parents in the support group may already belong to volunteer committees that are open to parents and interested community members (e.g., Association for Retarded Citizens committees, Community Advisory Council for Special Education (CAC), Area Board Committees, Developmental Disabilities Council, Special Education Network, etc.). If they're not members, the facilitator and interested parents will need to investigate how these agencies choose their committee members and which parents' schedules will permit them to belong. Since many committees meet on a monthly basis, it may be possible for parents to attend on a rotating basis if no one is able to make a membership commitment. The minimum goal should be to have a representative in attendance at all key meetings. In this way, although the representative won't have voting power, he or she will be able to report the current concerns of the parent group to the committee, and communicate committee actions back to the group.

A. Committee Membership and Newsletter Contributions as Strategies to Enlist the Support of Existing Agencies

Having the credibility of an established agency committee behind them will be helpful to the parent group in cases where major concerns are involved, such as a moratorium on the funding of some services, staff cutbacks in the schools, and the like. In addition, the Association for Retarded Citizens, United Cerebral Palsy, and several other organizations send newsletters to their memberships on a regular basis, so that they can communicate effectively with large numbers of people in the community. The parents may be able to contribute articles about their concerns to these agencies' newsletters.

B. Inviting Agency Staff to Parent Group Meetings

Another strategy for involving community agencies with the parent group is to invite community agency staff members or volunteer committee members to a parent group meeting. You may already be doing this for topical presentations, where these individuals might be the guest speakers on such topics as vocational training, legal rights, group homes, or normalization. When you hold these meetings, a period of time should be reserved for allowing the group to convey its priorities to the agency representative. The group can then also ask about the current goals, future plans, and range of service provided by the agency.

C. Publishing a Parent Newsletter

Still another strategy for keeping other organizations involved is for the parent group to publish its own monthly or bimonthly newsletter (see the REACH sample, on p. 83). Putting out a newsletter is most practical in a school district that has more than one parent group, or where the group represents large numbers (i.e., more than 50 parents in the community). A newsletter can be as elaborate as resources allow. For example, it can be professionally printed, or it can be typed on ditto masters at home, and reproduced using a school's ditto machine. It can be mailed individually, or sent home with students. Copies can also be dropped off at agency offices.

A parent group newsletter can be especially important for keeping up a good flow of communication between integrated school sites so that parents can stay in contact with each other. If you publish a calendar of the events that are occurring at different sites, parents will be able to attend presentations of interest to them, and can meet parents of other severely disabled students. It's also helpful to include information about pending legislation or changes in school policy, and what the recommended actions are on these. A schedule of board of education meetings and their location can be included as well.

A newsletter can also serve as a vehicle for publicizing large community events, such as an Awareness Fair about people with disabilities. Volunteers can also be recruited through the newsletter to work in classrooms, provide childcare, become awareness education (i.e., learning station) leaders, or offer other vital assistance.

Individual parents might contribute anecdotes, recipes, descriptions of toys they've adapted for their child's use, information about new recreation programs, or notes on accessible restaurants, on dentists and doctors with whom they've had positive experiences, relevant book reviews, and the like. The possibilities are vast.

Perhaps most important is the opportunity a newsletter provides for making editorial or policy statements. This type of communication from parents to parents, from parents to the school district, and from parents to community service providers will increase the visibility of the parent group and cause agencies to take notice of its activities. At the school site level, principals and teachers should receive the newsletter. Special education central office administrators should be on the mailing list, as well as executive directors of specialized service provision agencies and some generic service agencies.

Funding for a newsletter may be possible through the PTA (who might cover reproduction costs and include the newsletter with other PTA bulk mailings) or through parent group dues. Alternatively, a fund raising event (e.g., a flea market) could be scheduled. An additional possibility is to apply to local public or private foundations for a small grant. And, if the school district's Community Advisory Council for Special Education does'nt have its own newsletter, the group might consider pooling resources with them to put out a joint publication.

As we've stressed before, translations of the newsletter into those languages spoken by the parents the newsletter addresses is a necessity. The most readily available source of translators will probably be the parents themselves. Having such translations done will also be good for creating positive public relations with neighborhood groups or associations representing nonEnglish speaking constituencies in the community (e.g., Arriba Juntos, Chinatown Development Center, etc.).

Project REACH found that our major task initially was to present and disseminate accurate information about our goals to large numbers of school district personnel, parents, and community agencies (see Project REACH's publication, the Project REACH Administrator's Manual, 1983). A parent-community newsletter can achieve these same ends for a parent group, and establish the group's credibility in the community. A copy of one of Project REACH's newsletters appears on the following pages.

reach RAP-UP

A Parent-Community Newsletter

Vol. 1 No. 2 February, 1982

Dear Reader,

This is the second issue of a newsletter which is directed primarily to the parents of students in the six REACH project-SFUSD classrooms for severely handicapped students at Ortega, Cobb, Sutro and Presidio schools. Its goal is to stimulate greater parent involvement in REACH parent group activities, keep REACH parents informed of these and other school district and community events relating to special education and their children, and to let the community know about us. We also hope that it can become a forum for parents to voice concerns that they have and share information with each other. We are looking for parents and community agency personnel who would like to contribute articles, and hope to hear from you in the next few weeks so we can plan future issues! We're interested in any reactions or suggestions you may have, and we'd also like to hear from anyone who would volunteer to translate the newsletter into Spanish, Cantonese or Tagalog each month. Hope to hear from you soon!

Ann T. Halvorsen
Parent-Community Coordinator
Project REACH
469-1306

¡A Nuestros Padres Hispanoparlantes!

Nos hemos visto algunos de Uds. a las reuniónes de los padres a las escuelas Ortega, Cobb, Sutro y Presidio. A Presidio y Ortega hemos provisto con una intérprete para estar seguros que los padres hispanoparlantes pueden participar totalmente a las reuniónes.

Estos grupos de padres han provisto una oportunidad para los padres a conocerse, compartirse experiencias, y a escuchar presentaciónes sobre asuntos de interés a ellos como los derechos docente legales del alumno y el padre, entrenamiento vocacional de la gente impedido, etc. ¡Esperamos que todas de Uds. asistan estas reuniónes!

Uds. recibirán notas de la escuela cuando una reunión va a pasar. Hagan el favor de marcar la porción de estas notas y entraguenselas para avisarnos que puede venir para que podamos proveer una intérprete a la reunión para Uds.

¡Entreguese a las reuniónes ahora! Necesitamos su participación para asegurar la mejor educación que es posible para su hijo.

Jose Ortega School

On Thursday, February 18, several parents attended a meeting with Nan Graham, the classroom teacher, and her staff; Warren Kane, Ortega's principal; and Ann Halvorsen. Social programs for students were the topic of the meeting, and videotapes of each child working on their social objectives were provided by REACH site coordinator, Carola Murray. Nan explained each program to the group, and discussion followed about doing social goal programs at home. Each parent filled out a form about goals they would like help with working on at home so that Nan and Ann can plan with them. Topics for future meetings were discussed, and Beverly Austin suggested training for parents on the best ways to answer brothers' and sisters' and others' concerns about the handicapped child in the family. Many of you from Ortega and other schools may have thoughts or suggestions about this idea -- please call and let Ann know! Another idea of Beverly's was a workshop about toys that can be used by children with specific motor or sensory handicaps. Are you interested? Let us know!

Special Olympics

We hope that all interested parents were able to get their medical and registration forms in by February 19 so that their children could participate! Debbie Spehn, one of Sutro School's teachers has volunteered to participate in the Saturday program, and hopes to see some of her students there. Dr. Leonie Watson, Room Mother at Sutro for Debbie's class, and her husband Dr. Richard Watson, were especially helpful in performing physicals for interested students in the two classes. Thank you to Debbie, Leonie and Richard!

Sutro School

On February 25 at Sutro, parents are ha a potluck dinner together with their families. We hope to see both familiar and new faces in the group, so that we can plan future activities together. In January Michael Rosenberg and Tom West from the ARC spoke with parents about how to get services needed through the Regional Center, especially after-school programming. It was very helpful information! We have a new teacher on the staff at Sutro! As all the parents know, Austin Shaffer -- who had been teaching the class since September -- and who came to Sutro from Second Community and Lombard Schools, has decided to participate in California's semi-retirement plan. He will be working part-time until his full retirement in the future. We know what a difficult decision this has been for Austin, and he will be missed by his students, parents and all the staff at Sutro and REACH.

We are happy to welcome June Tonai, the new teacher of the class, who comes to Sutro from San Francisco State University's graduate training program for teachers of severely handicapped students. June worked at Cobb School last semester. We're very glad to have her with us!

Presidio Middle School

In February, Kathy Gee, Cecile Briar and Ann will be having a dinner for the parents from Kathy's class at her house! Kathy plans to show slides about the Peer Tutoring and Special Friends programs. The students who work with Kathy's class in these programs are developing a script to go with the slides! We hope that the dinner will give parents a chance to relax, talk and get to know each other and staff informally, and discuss what direction they would like to go in with future meetings.

AWARENESS FAIR '82:
People with Special Needs

A community awareness day for and about people with special needs of all ages is being planned for Friday May 7 at the Civic Center Plaza from 11 A.M. to 6 P.M.! Ann Halvorsen of REACH, along with Clara Giannini of the ARC and Ladde Farfan and Pat Langdell of the Community Advisory Council for Special Education are busy planning this event. We have received the personal endorsement of Hank Marshall, Associate Superintendent of SFUSD, and we will be presenting a Board of Education resolution in support of Awareness Fair '82 at the next two Board meetings, February 23rd and March 9th. We will also be asking for the support of the Mayor's office and all community agencies and groups interested in participating! Awareness Fair '82 is designed to promote communication and attitude change toward all people with special needs, by increasing awareness of people's abilities and potential.

We plan to have speakers, displays, and performances at this exciting event. Right now we're soliciting co-sponsorships from agencies and corporations. We could use your help making follow-up phone calls for us, or in many other ways! Please call Ann (469-1306) or Clara (931-3330 at ARC) if you can help with Awareness Fair '82.

In this time of budget cuts and concerns about the future of special education programs nationwide, it is more important than ever that the community is aware of our childrens' needs and potential. Please join us in planning this event!

Community Advisory Council (CAC) for Special Education

Two important and informative meetings took place in the past month. On February 4 in the Board of Education room, Hank Marshall (Associate Superintendent of SFUSD), Linda Caputo (Program Manager for Special Day Classes) and Hal Solan (Program Manager of Site Assessment workers) gave reports on the status and future of various special education programs in the district. On February 16 the CAC met at Presidio Middle School. The CAC will be holding one of their 2 meetings per month at a school site in an effort to attract more parents to their meetings, and let local schools get involved as well. Tony Anderson, Presidio's principal attended the meeting, as well as several special education teachers and staff. The group went over the CAC parent handbook section on rights and responsibilities of parents. Other issues were discussed, such as the question of integrated summer school programs for special education students. Leila Heilbrun, SFSUD staff liaison to the CAC, will be exploring this issue with the district.

The next CAC meetings will be March 4th (Thurs.) at the Board of Education room (Rm. 30, Fell Street side of 135 Van Ness offices), March 16th and April 1. We'll let you know about locations and agenda.

Association for Retarded Citizens (ARC) News

Kathy Gee, Presidio Middle School teacher, was recently elected to the Board of Trustees of the ARC! Congratulations to Kathy -- we know how important her input will be in ARC's planning for community-based programs for severely handicapped people in San Francisco.

ARC's Education Committee, chaired by Clara Giannini (Presidio parent and vice-president of ARC) continues to meet monthly and is always looking for interested parents who want to join. The committee has been able to obtain figures from SFUSD about the exact numbers of severely handicapped students who will be graduating over the next five years, so that ARC can plan programs to meet their needs.

PLEASE SEND BACK the slip below if you are interested in getting involved in the newsletter or other programs mentioned! Mail to: Ann T. Halvorsen, Project REACH, 700 Presidio Avenue #206, San Francisco, 94115. (Or call me at 469-1306)

Check any that apply:

1. I am interested in contributing articles to the REACH Rap-Up Newsletter [ ]

2. I would like to volunteer to translate the newsletter into:
   - Cantonese [ ]
   - Spanish [ ]
   - Tagalog [ ]

3. I want to help with Awareness Fair '82! [ ]

4. Other ______________________________ [ ]

Name: ______________________________

Address: ______________________________

Phone Number: ______________________________

6. PROGRAM EVALUATION

Evaluating the parent group's activities on a formative (ongoing) and summative (concluding) basis is both desirable and possible. As some researchers have pointed out, the existing data base on the effectiveness of parent involvement programs is far from satisfactory (cf. Halvorsen, 1983;Turnbull & Turnbull, 1982). There have been no systematic studies that have tried to determine what types of programs are successful with particular "types" of parents of severely disabled students. To help fill this gap, it's therefore crucial that you initiate evaluation activities as soon as your parent group has been established.

A. Formative Evaluation

1. Topical Presentations.

Once your group has established its priorities as to which topics are most important, you and your group can be writing objectives or short and longterm goals. When it's a group objective to acquire information on a specific topic, this will be relatively easy to evaluate. For example, the group and/or facilitator can develop feedback forms on topical presentations that can be filled out at the close of the session. Knowledge surveys on specific topics will also help parents determine whether they've increased their level of understanding (see the Appendix for Mt. Diablo Legal Rights Survey as an example of a knowledge survey). The information gained from using these types of feedback forms and surveys should be shared with the group at the next session. It can help the group in planning future sessions or in advising guest speakers of the type of workshop or presentation that's most appropriate for the parent group.

Once parents begin conducting their own community awareness training activities, they'll find feedback essential. Again, a short questionnaire can be developed for participants to fill out at the end of the session. The answers will provide station leaders or trainers with valuable information as to how to proceed.

2. Facilitator effectiveness.

This is also a priority area of formative evaluation, which will be equally important whether the facilitator is a parent or a professional.

If the facilitator has conducted needs assessments or inventories at the beginning of the program, he or she should have a good base for initiating a parent support group that meets parents' needs. However, ongoing feedback is required to ensure that the facilitator continues to be aware of the group's reaction to the program and to her or him. Periodic evaluation forms can be filled out by the group: forms can be used to encourage discussion about the facilitator's strong and weak areas (see the form at the end of section B. One way to conduct this discussion is to write goals for the facilitator as a combined effort of the facilitator and the group).

B. Summative Evaluation

The facilitator and/or parent group may be interested in a more systematic investigation of other aspects of the parent program. One example might be the effects of various components of the parents' participation in, and satisfaction with, their severely disabled child's school program. Pursuing this type of evaluation study could be an appealing project for graduate students in special education university programs, especially if they're student teaching in district schools. Or, if the facilitator is associated with a university program, he or she may wish to set up a similar research study.

On p. 91, you will find a Parent Questionnaire (Anderson & Halvorsen, 1983), that the California Research Institute (at San Francisco State University) is using in cooperation with teachers and parents of students in San Mateo County's Special Education Program for students with severe disabilities. The specific purpose of the questionnaire is to examine the level of the severely disabled child's participation in family activities, and the level of assistance required by him or her before and after implementation of an integrated school program. In addition to this "pre" and "post" measure, a matched group of parents of nonintegrated students will also participate in the study. In this way, changes within each group can be examined, as well as differences between the two groups.

Parent questionnaires can also be utilized to examine whether changes in participation, satisfaction, and expectations occur after a parent involvement program is started. Parents who choose not to participate in the program can be matched with parents in the support group, and both groups can fill out the questionnaire in the fall and spring. Given large enough samples and access to computer programs, data can be analyzed to determine if there are statistically significant differences from pre to posttest, within and between groups. This type of information can be helpful in determining whether the parent involvement program is having any direct impact on the severely disabled students in question.

To supplement the questionnaire data, teachers or the parent facilitator might look at some additional measures of parent involvement, such as how many IEP goals parents contribute, how many classroom observations parents make during the year, how many requests parents make for home instructional programs, etc.

We can't stress too heavily the need for program evaluation of parent involvement activities. For too long, professionally-designed programs have treated parents of severely disabled students as a homogeneous group, with similar needs and interests. The overall purpose of this manual is to outline a parent involvement model that can be adapted by local parent groups to be responsive to your own needs.

On the following pages, we've provided a facilitator feedback form and a parent questionnaire that you can modify to suit your evaluation plan. Information on keeping your program cost-effective follows.

Project REACH
1982

Parent Group Leader-Facilitator
Feedback Form

For each item, please circle the number that best describes the facilitator of your parent group.

1. Encourages discussion by all members of the group.

1	2	3	4
rarely	sometimes	quite often	always

2. Responds promptly to parent concerns.

1	2	3	4
rarely	sometimes	quite often	always

3. Helps the group define its priorities and stay on task.

1	2	3	4
rarely	sometimes	quite often	always

4. Demonstrates adequate knowledge of community resources.

1	2	3	4
rarely	sometimes	quite often	always

5. Is open to suggestions and constructive criticism.

1	2	3	4
rarely	sometimes	quite often	always

6. Is helping parents in the group to become effective advocates (rather than just advocating <u>for</u> you).

1	2	3	4
rarely	sometimes	quite often	always

7. Is able to show respect for varied points of view.

1	2	3	4
rarely	sometimes	quite often	always

Other comments:

106

Family Code #: ______________

California Research Institute

Parent Inventory

Parent(s) who completed this form: Mom ____ Foster Parents ____
Dad ____ Natural Parents
Both ____ Group Home Parents ____

Code # child: ______________________

Age of child: ______________________ Number of parents living in the home ________

Number of people living in the home ________ Number of brothers & sisters living at home ______

Ages of brothers ______________________ and sisters ______________________

District or County ______________________________________

School site ______________________________________

Disabilities ______________________________________

Equipment used ______________________________________

1. Please list all of the specific environments under each category where your child and family function. Check the appropriate column to describe his/her level of independence for each environment listed.

Home environments (e.g., yours, relatives, neighbors, etc.)		needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	could/does go there alone
Other Family Members	Child with Disability					
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

__________ stayed the same

__________ increased

__________ decreased

Comments:

KEY: A - always
U - usually
O - occasionally
N - never

Respite environments
(e.g., day care, babysitter's home,
respite home, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/doe go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Eating environments
(e.g., regular restaurant, fast food
restaurant, ice cream parlor, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/[illegible] go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

hopping environments
e.g., grocery stores, malls, department stores, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/doe go there alone
	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

____ stayed the same
____ increased
____ decreased

Comments:

rvice environments
(e.g., laundromat, repair store, gas station, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/doe go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

five years, do you expect that the level of your child's independence in this environment will have:

____ stayed the same
____ increased
____ decreased

Comments:

Health-related environments
(e.g., doctor's office, dentist's office, therapy, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/does go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Personal fitness environments
(e.g., barber shop, beauty parlor, health club, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/d[illegible]es go the[illegible] alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Community recreation or social environments (e.g., movie theatres, YMCA, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/does go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

S[illegible]rts environments (e.g., swimming pool, skating rink, bowling alley, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/does go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

[illegible] five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Cultural environments
e.g., museums, concert hall, capitol building, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/do go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Vacation environments
(e.g., campgrounds, motels, hotels, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/do go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Religious environments
(e.g., church, Sunday school, church functions such as picnics, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/doe go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

____ stayed the same
____ increased
____ decreased

Comments:

E[illegible]ational environments
([illegible]g., school, lessons such as piano, dance, etc.)

Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Could/does go there alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

[illegible] five years, do you expect that the level of your child's independence in this environment will have:

____ stayed the same
____ increased
____ decreased

Comments:

Public transportation environments (e.g., buses, trains, etc.) Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/d go ther alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

Job related environments (e.g., paper route, factory, etc.) Other Family Members	Child with Disability	needs help all the time	needs help most of the time	needs help occasionally	doesn't need help but needs supervision	Coul[illegible]c go t[illegible]e alone
1.	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

_____ stayed the same
_____ increased
_____ decreased

Comments:

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Other Family Members	Child with Disability	needs help all the time	needs help most the time	needs help occasionally	doesn't need help but needs supervision	Could/c go ther alone
[illegible]	A U O N					
2.	A U O N					
3.	A U O N					
4.	A U O N					
5.	A U O N					
6.	A U O N					
7.	A U O N					
8.	A U O N					
9.	A U O N					
10.	A U O N					

In five years, do you expect that the level of your child's independence in this environment will have:

____ stayed the same
____ increased
____ decreased

Comments:

2. Check any of the factors listed which have an effect on your son's or daughter's participation in any of these environments:

____ He/she doesn't know how to interact with others in the environment.

____ He/she doesn't know how to participate in that environment.

____ He/she is unable to participate in the environment as a result of a handicapping condition (e.g., physical limitations or medical fragility).

____ He/she acts inappropriately in the environment (too noisy, can't sit still, etc.)

____ People react negatively to my child in these environments.

____ It is difficult to transport the equipment my child needs to other environments.

____ Environments are not accessible to my son's or daughter's equipment (e.g., no elevators, doorways too narrow).

____ He/she is too young for this activity.

____ He/she is too old for this activity.

3. An interaction is a situation in which another person talks to the child and/or the child communicates in some way with another person. List the people with whom your child interacts on an ongoing basis.

____________________ ____________________
____________________ ____________________
____________________ ____________________
____________________ ____________________
____________________ ____________________
____________________ ____________________

4. Check the type(s) of communication system(s) which your child understands:

Modeling/demonstration ____
Gestures ____
Verbal speech ____
Pictures ____

Sign Language ____
Written Word ____
Nonword symbols ____
Eye contact ____

Other (explain) ____
____
____
____

____
____
____
____

5. Indicate the way(s) your child communicates with you and others.

Grunts or non-word vocalizations ____
Talks ____
Points to things ____
Pulls people around ____
Uses sign language ____
Shows us pictures ____
Facial expressions ____

Shows us real object ____
Writes ____
Points to written word ____
Points to nonword symbols ____
Tantrums, screams, etc. ____
Looks at what he wants, looks at you ____

Other ____
____
____
____

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Parent Inventory/CRI

Environments examples list

Home:	Yours		Page 1
	Relative		
	Neighbors		
Respite:	Day Care		Page 2
	Babysitter's home		
	Respite home		
	Relative's home		
Eating:	Regular restaurant		Page 2
	Fastfood restaurant		
	Ice cream parlor		
	Deli		
	Others' homes		
Shopping:	Grocery stores	Deli, small market	Page 3
	Malls	Drugstore	
	Department stores	Specialty shops	
Service:	Laundromat	Gas station	Page 3
	Cleaners	Bank	
	Repair stores	Post office	
Health related:	Doctor's office	Therapy	Page 4
	Dentist's office	Hospital	
	Clinic (e.g. orthopedic)		
Personal fitness:	Barber shop	Exercise class	Page 4
	Beauty parlor		
	Health club		
Community Recreation or Social:	Amusement park	Brownies	Page 5
	Zoo	PTA/Parent Group	
	Rec center	Movie theater	
	Day camp	Bridge/Supper etc. Club	
	Park/playground	Lodge/Kiwanis	
	YM/YWCA	Beach, pool	
	Boy/Girl Scouts	Boating	
		Dances	
Sports:	Swimming pool	Track	Page 5
	Hiking	Golf course	
	Skating rink	Bowling alley	
	Special Olympics		
	Spectator sports (Little League, football, baseball, basketball, soccer game)		
Cultural:	Museums	Library	Page 6
	Art show	Play	
	Lectures	Puppet show	
	Ballet	Play	
Vacation:	Campgrounds	Boats	
	Motel/Hotel	R-Vs	
	Cabins	Visit relative/friends' homes	Page 6

Religious:	Church Temple Church picnics Sunday school	Meetings Dinners Bible study	Page 7
Educational:	School Music or other lessons Dance lessons Night classes	Tutoring Speech therapy	Page 7
Public transportation:	Buses Bart Taxicab	School bus Train	Page 8
Job-related environment:	Paper route Factory Service (e.g. doctors, domestic, lawnwork, restaurants, sales)	Office	Page 8
Other - Anything not covered above			Page 9

C. Cost Effectiveness

Throughout its three-year project, REACH employed one parent-community coordinator at 50% time. As our population of families grew from five during the first few months to 85 by the end of the second year, it became clear that strategies for parent involvement needed to be well-defined to guarantee all parents an equal opportunity to participate. Defining the level of parent involvement was necessary to ensure that the coordinator's 20 hours per week were equitably distributed across school sites.

As a reader and prospective adopter of REACH parent activities, the project thought that you might benefit from seeing a breakdown of the time involved in carrying out the activities described in this manual. You can use the information as a basis for planning time and costs for your program. One point to keep in mind is that before implementing the program, the parent facilitator spent several weeks reviewing the relevant existing literature, surveying local programs, and developing or refining inventory forms and questionnaires. While you may choose to repeat this process yourselves, we hope that the PACT has succeeded in shortening this step for you.

PACT Activities Time Breakdown

	Activity	Time per Month
1.	Parent support group monthly meetings (3-4 per month at different schools)	15 hours (with preparation)
2.	Meetings with teachers to plan parent meetings, exchange information (two to three per month)	10 hours
3.	Individual parent contacts: inventories, advocacy before and/or at IEPs, visits with parents to adult or residential programs or schools, liaison with community agencies, location of resources, connecting parents with other parents, etc.	12 hours
4.	Membership on or attendance at committees with parents and agencies, e.g.:	
	• ARC (Education Committee)	4 hours
	• CAC for Special Education (attendance at monthly meetings)	4 hours
	• Area Board V Advocacy & Monitoring Committee	3 hours
	• Awareness Fair Steering Committee	4 hours

5.	Newsletter preparation (not including typing, xeroxing)	7 hours
6.	Information provision re: legislative alerts, important meetings, etc.	8 hours
7.	Special projects (e.g., integration training) and/or general administrative duties (e.g., staff meetings)	10 hours
8.	PTA school site meetings (maximium one per month)	3 hours
	Total	80 hours per month

APPENDIX

A. Where do I go for help/information?

Resources for topical presentations and parent support.

Keep in mind that there are similar resources available within your school district and community for this purpose. Don't reinvent the wheel!

1. Legal rights/advocacy: The following may be present in your community, or may be contacted for materials and information.

a. Protection & Advocacy Inc.

Mr. Al Zonca, Executive Director
1400 'K' Street, Suite 07
Sacramento, CA 95814
800-952-5746

Each state has its own. May be called "Advocacy Services"

Contact your State Department of Education for information

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b. Community Alliance for Special Education (CASE)

Joe Feldman
1031 Franklin St., Ste. B5
San Francisco, CA 94109
415-928-2273

Only in San Francisco Bay area; privately and publicly-funded organization that advocates for students and their parents

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c. Center for Independent Living (CIL)

2539 Telegraph Avenue
Berkeley, CA
415-548-4274
TTY 548-4282

National Organization. There's a network of Independent Living Centers throughoout the country

Independent Living Project

4429 Cabrillo Street
San Francisco, CA
415-752-8186

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d. Closer Look

P.O. Box 1492
Washington, DC

Gives out free information; referrals for resuorces

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e. Parents Campaign for Handicapped Children and Youth

1201 16th Street N.W.
Washington, DC 20036
202-833-4160

Information and referral center

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f.	Coordinating Council for Handicapped Children 222 South State Street Room 412 Chicago, IL 60604 312-939-3513	Puts out good publications and legislative newsletter (newsletter is focused on Illinois State as well as on federal information). Charges nominal fees for materials. Send for order blanks.
g.	P.A.C.E.R. Center Inc. 4701 Chicago Avenue South Minneapolis, MN 55407	Has good materials on legal rights but these need some alteration for use outside Minnesota.
h.	Children's Defense Fund Branch office: 444 Pearl Street Monterey, CA 93940	1763 "R" Street N.W. Washington, DC 20009 Lobbies for all children's rights throughout the U.S. Will give advice and information.
i.	Your local district's Community Advisory Council for Special Education or Special Education Advisory Board which is composed of parents, district and agency representatives	in San Francisco: Bill May, Chairperson, CAC, SFUSD, 135 Van Ness, San Francisco, CA 94102. In California these committees are mandated by the Master Plan for Special Ed.
j.	Legal Services for Children Carole Brill 149 9th Street San Francisco, CA 94103 415-863-3762	Provides general assistance, as well as specific workshops and training for parents. Advocates for all children.
k.	Center on Human Policy 216 Ostrom Avenue Syracuse, New York 13210 (P.O. Box 127 University Station Syracuse, NY 13210)	Human Policy Press (P.O. Box 127 Has put out several excellent resources on mainstreaming and integration, as well as policy statements regarding rights of all disabled persons. Send for catalog.

l. Association for Retarded Citizens (ARC) in San Francisco

Clara Giarnini, President
Michael Rosenberg, Executive Director
3110 California Street
San Francisco, CA 94115
415-931-3330

National headquarters:

NARC
2709 Ave. "E" East
Arlington, Texas 76011
Or see phone directory for your local chapter. Provides advocacy, adult vocational and residential programs, newsletters, parent support, and several publications.

m. Area Board Developmental Disabilities in S.F. Bay area: Area Board V (Alameda, Contra Costa, San Francisco, Marin, San Mateo counties)
Kathleen Fennell, Director
1111 Jackson Street
Oakland, CA 94607
415-464-0439

Puts out excellent newsletter through its Special Education Network. Free. Legislative information for California and nationwide. Call to be put on mailing list. Also has free film lending library (see Appendix D). Every county in California is part of an Area Board.

n. Developmental Disabilities (D.D.) Council in San Francisco

Randolph Fleming, Chairperson
101 Grove Street
San Francisco, CA 94102
415-558-3583, 3684

Each area in California has its own voluntary council, overseen by the state D.D. Council in Sacramento. This group can make specific recommendations to the Department of Developmental Services regarding their community and program development.

o. National Center for Law & the Handicapped

1235 N. Eddy Street
South Bend, Indiana 46617

Provides information, advice, and referral.

p. Center on Developmental Disability Law (CDDL)

1103 Grand Avenue
Kansas City, MO 64106
816-474-4092

A project that offers training and technical assistance on the right of developmentally disabled people. Has a staff of four attorneys.

q. Disability Rights Education & Defense Fund (DREDF)

2032 San Pablo Avenue
Berkeley, CA 94702

Kim Swain, Staff Attorney
Arlene Meyerson, Staff Attorney
Mary Lou Breslin, Attorney
Nonprofit group providing advocacy and legal aid to families with disabled children.

2. Adult Vocational Programs/Resources

a.	Association for Retarded Citizens (ARC) in S.F. Michael Rosenberg, Executive Director 3110 California Street San Francisco, CA 94115 415-931-3330	See phone directory for local chapters (see 1., 1.)
b.	Personnel Development Unit Project P.A.C.E./TRG Bill Rosenberg Alameda USD - SERN 313 W. Winton Hayward, CA 415-786-0901	Part of the California State Education Resource Network. Workshops for teachers and parents statewide
c.	President's Committee on Employment of the Handicapped Washington, DC 20210 202-653-5010	Has free periodical
d.	Project P.A.V.E. (Parents Advocating Vocational Education) (part of A.1.e.) 1201 16th Street Washington, DC 20036 202-833-4160	Information and referral
e.	Rehabilitation Services Administration (now part of Office of Special Education and Rehabilitation Services) 330 "C" Street S.W. Washington, DC 20201 202-245-8492	Federal agency overseeing rehabilitation services in your state.
f.	Technical Employment Project (TEP) Cory Gaylord-Ross, Project Manager Robert Gaylord-Ross, Principal Investigator c/o Robert Gaylord-Ross San Francisco State University ED 104 1600 Holloway Avenue San Francisco, CA 94132 415-469-1300	Provides opportunities for work experience in industrial settings. High school students from Richmond School District with range of disabilities.

g. **United Cerebral Palsy Association**

314 Mission Street
San Francisco, CA 94103
415-543-3135

Provides advocacy, preschool and adult programs.

National:

66 East 34th Street
New York, NY 10016
212-481-6350
(see phone book for local chapters)

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h. **Mount Diablo Community Rehabilitation Workshop**

191 8th Street
San Francisco, CA 94103
415-431-9200
David Glassberg

Provides adult day work programs in the San Francisco Bay Area.

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i. **Over-21 Project**

Willa Lindsay, Board Chairperson
Laney College
900 Fallon Street
Oakland, CA 94607
415-465-9532

State-funded project now "vendorized" by Regional Center of the East Bay for adults with severe disabilities. ("Vendorized" refers to the fact that a pay rate for the service provider has been established by the state.) Provides educational and vocational training within an integrated community college setting.

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j. **Golden Gate Regional Center**

100 Mission Street
San Francisco, ca
415-546-9222
Carmen Castro
Sherry Thompson, Clients Rights Advocate

Regional Center of the East Bay

2201 Broadway
Oakland, CA 94612-3402
415-451-7232
Jose Maltos, Exec. Director

The State of California contracts annually with a network of privately operated nonprofit regional centers* to provide information, diagnosis, referral and ongoing case management on a "fee for service" basis to all individuals who are diagnosed as having a 'developmental disability' (e.g., cerebral palsy, epilepsy, mental retardation). The regional center then provides funding to specific vendors (e.g., adult vocational programs, recreation programs, respite care providers) for the services they provide to individuals.

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* see the Glossary

D. Recreational Services/Resources

a.	American Red Cross National Headquarters 18th and "E" Strets N.W. Washington, DC 20006	May have swimming programs or instruction in your local area that is designed for disabled children and adults.
b.	Special Olympics in S.F. National Headquarters 18th and "E" Streets N.W. Washington, DC 20006 In San Francisco McLaren Lodge Recreation and Parks Department Stanyan and Fell Streets San Francisco, CA 415-221-6575 Lance Lindsay	Recreational ans sports programs on an ongoing basis as well as regional and national competitive events.
c.	Recreation Center for Handicapped 207 Skyline Boulevard San Francisco, CA 94132 415-665-4100	Only in San Francisco. Has programs for children and adults; summer, after school, and day activities (nonintegrated).
d.	Challenge to Learning 924 Balboa Street San Francisco, CA 415-221-9200 Arthur Kolach, Director	Provides after-school recreation programs in San Francisco for disabled students only.
e.	Project PLAE (Play and Learning in Adaptable Environments)	Integrated summer program in Berkeley, California only, (but open to all San Francisco Bay Area students). Washington Elementary School Environmental Yard. For children of all abilities ages 6-16. Week long workshops - 15 nours for $25.00 in 1982. Scholarships also. Arts, crafts, games, theater, adaptive physical education. Call Susan or Daniel at 415-845-7549.

f. National Committee, Arts for the Handicapped

1825 Connecticut Avenue N.W.
Suite 418
Washington, DC 20009
202-322-6960

Information, special projects; helps to promote awareness of abilities of disabled studens.

g. Let's Play to Grow Clubs

c/o Eunice Kennedy Shriver
Joseph P. Kennedy, Jr. Foundation
1700 'K' Street N.W.
Suite 205
Washington, DC 20006
202-331-1731

Network of clubs to help parents learn and adapt play activities for their disabled children. Publishes play guides.

4. Sibling Support Networks

a. SHARE (Siblings Helping Autism Through Resources & Energy)

Laura Preiser and Kenny Laureys
1234 Massachusetts Avenue N.W.
Suite 1017
Washington, DC
202-783-0125

A committee of the National Society for Children and Adults with Autism. Puts out a newsletter, siblings' scrapbook; holds national meetings, offers a book list. $3.00 yearly dues.

b. Sibling Information Network

P.O. Box 791
Peabody College
Nashville, TN 37203
c/o Peggy Ogle

Newsletter, materials and information center.

5. Adaptive Equipment Information

Designs adaptive equipment for persons with disabilities.

a. Rehabilitation Engineering Center
Children's Hospital
Stanford University
Palo Alto, CA

b. Equipment Exchange for parents:

- Ruthann Dodge
  2 Bates Street
  Danvers, MA 01923
  617-774-4817

Parents in these areas can contact these equipment exchanges to trade items that their children have outgrown for other adaptive equipment which another parent has traded in.

- Clearinghouse for equipment exchange

  Eugene Patrick, Resource Coordinator
  Children's Rehabilitation Center
  Route 250 West
  Charlottesville, VA 22901

c. California Children's Services (formerly Crippled Children's Services)

101 Grove Street
San Francisco, CA
415-558-3406

These services are provided under the Maternal and Child Health Funding of California (Public Health). Information, referral, diagnosis, clinical recommendations, provision of adaptive equipment, if the individual qualifies medically and financially.

6. Normalization/Integration

a. Project REACH:

Write to/call:

Chesca Piuma
Director, Project REACH
612 Font Boulevard
San Francisco, CA 94132
415-469-1306

Additional resources available:

Project REACH Administrator's Manual (PRAM)
Awareness & Inservice Manual (AIM)
Inventory Processes for Social Interaction (IPSI)
Educational Assessment of Social Interaction (EASI)

b. Hawaii integration project special friends trainer's manual: Starting a project in your school

Hawaii Integration Project
Department of Special Education
Wist Hall #208
University of Hawaii
Honolulu, HA 96822

A how-to guide that resulted from this three-year "sister project" to REACH in Hawaii

$5.00 charge

c.	Better Understanding Group Easter Seal Society of Marin 70 Skyview Terrace San Rafael, CA 94903 Joan Kilburn	Has training manuals and kits for presenting workshops about people with disablilities. Charges $20.00 for kit.
d.	Mainstream Information Center (MIC) Mainstream, Inc. 1200 15th Street N.W. Washington, DC 20005 202-833-1162 -- 9-5 A.M. Eastern time	MIC will anwer questions of interest to disabled consumers employers, parents, and professionals. A nonprofit group to support integration. Has free publications.
e.	Project Co-Action (Association for Retarded Citizens in San Francisco) Michael Rosenberg, Executive Director 3110 California Street San Francisco, CA 94115 415-931-3330	Project Co-Action was a special project of the San Francisco ARC, which provided regional and local workshops to "generic" serrvice providers (e.g., Department of Social Service personnel) to acquaint them with developmentally disabled people and their needs. Their manual, Whose Community is It, provides information on the process and content for such workshops, and focuses on issues of normalization, integration and individual rights. It can be purchased from ARC-SF for $15.00.
f.	Center for Independent Living (CIL) 2539 Telegraph Avenue Berkeley, CA 415-548-4274 TTY 548-4282 (see 1.c.)	Independent Living Project (ILP) Pat Christiansen 4429 Cabrillo San Francisco, CA
g.	California Research Institute on the Integration of Students with Severe Disabilities (CRI) Wayne Sailor, Principal Investigator 612 Font Boulevard San Francisco, CA 94132 415-469-1306	One of two federally-funded five-year institutes designed to collect comprehensive data on the best instructional practices within integrated settings, and to document the transition process across a variety of school districts.

7. Parent Networks and Suggested Publications

a.	Parent Network 1301 E. 38th Street Indianapolis, IN 46205 317-926-4142	Volunteer parents providing linkage and information to other parents.
b.	Parent Resource Library Exceptional Child Center UMC 68 Utah State University Logan, Utah 84322 801-750-2034	Sends catalog free to parents; over 400 topics. Geared to residents of Utah, Idaho, Wyoming.
c.	The Exceptional Parent Journal for subscription, write to: P.O. Box 4944 Manchester, New Hampshire 03108	Monthly journal with practical information for parents of children who are retarded or have emotional or physical problems.
d.	ACCH Network (Chronic Illness & Handicapping Conditions: Meeting the Needs of Children & Families) 3615 Wisconsin Avenue N.W. Washington, DC 20016	Excellent national quarterly newsletter with information about conferences, local networks, new programs, etc. Puts out Spanish language pamphlets.
e.	The Association for the Severely Handicapped (TASH) 7010 Roosevelt Way N.E. Seattle, WA 98115 206-523-8446 Wayne Sailor, Ph.D., President, 1983 Liz Lindley, Executive Director Addie Comegys, Parent and Board Member	A national association with professional and parent membership. Excellent monthly newsletter. Quarterly journal with research reports and position papers. Annual dues fee. Has annual national conference.
f.	Parentele 1301 E. 38th Street Indianapolis, Indiana 46205 317-926-4142 (checks to Parent Network, Inc.)	National coalition created & operated by volunteers. Grew out of parents' need for ongoing & current information and contact with each other. Quarterly newsletter (Crisscross) to members. Annual national conference. Dues $10.00 for individuals & families, $25 for organizations.

9.	Support Lines Premature, Inc. 10200 Old Katy Road, Suite 100 Houston, Texas 77043	Quarterly newsletter for parents of premature and high risk infants and toddlers. Subscription fee, $5.00.

B. Legal Rights Survey

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MT DIABLO UNIFIED SCHOOL DIST
OMBUDSMAN
SUITE A1
2448 FLOYD LANE
CONCORD, CALIFORNIA 94520
(415) 671-2900

OFFICE OF
CHILD PARENT ADVOCACY
RESEARCH PROJECT

PARENT QUESTIONNAIRE

This questionnaire deals with laws relating to special education and is designed to determine parents current knowledge of these laws.

The questionnaire has three choices for each statement: True, False, and Don't Know. Please do not guess. If you do not know, or are unsure of, the law for a given statement, mark "Don't Know". Mark each statement by placing an "X" in the appropriate box.

This information will remain confidential.

Your cooperation is greatly appreciated.

	TRUE	FALSE	DON'T KNOW
1. If my child needs special education services, the law requires special class placement rather than providing special help for my child in a regular classroom.		✓	
2. I may participate in the process of my child's evaluation only if I object to the procedures used or the placement suggested.		✓	
3. Where special education services or equipment are required for my child's appropriate education, the school district may decide how much I may be asked to contribute to the cost.		✓	
4. If the school district requires diagnostic medical services for my child, the schools are required to pay for these services.	✓		
5. The written individualized educational program must contain yearly goals for my child, but short-term objectives are to be developed by his/her classroom teacher after placement.		✓	
6. After my child has been evaluated, the schools should hold a meeting for the purpose of informing me as to their findings and their recommendations for educational placement.		✓	
7. The primary purpose of the evaluation procedures is to determine the limitations imposed by my child's disability.		✓	
8. My child's individualized educational program must be limited to those services available through the school district.		✓	

Page 1 of 4

	TRUE	FALSE	DON'T KNOW
9. The school district may terminate special services for my child if they have provided me with a written notice of intent to terminate.		✓	
10. If I disagree with the school district's placement decision for my child, I may ask for a hearing before the Community Advisory Committee.	✓		
11. If I have questions about my child's school ability, I may refer my child for evaluation.	✓		
12. The individualized educational program developed for my child may be reviewed only at times during the school year designated by the school district.		✓	
13. My child's individualized educational program is a contract to provide service once it is signed by me and the district.	✓		
14. Even if I don't agree with the school's recommendations for my child, the district may place my child in a different program if they think it is best for him/her.		✓	
15. The district will not pay for the cost of travel to and from special school services for my child.		✓	
16. The schools may temporarily place my child in a special program without my consent until evaluation has been completed.		✓	
17. If my child needs services such as occupational therapy or physical therapy, the school is required to provide these services.	✓		
18. An attorney or other advocate may participate with school personnel in preparing my child's individual educational program (IEP).	✓		
19. Special Education Services for my child will be provided at no cost to me only if my child lives at home.		✓	
20. The school district may share without my permission, the results of my child's evaluation with other public agencies that offer services related to my child's disability.		✓	

	TRUE	FALSE	DON'T KNOW
21. The special education program and related services must be provided within one month after placement.		✓	
22. If my child receives special services as part of regular class placement, the district will not receive additional state funds for the services provided.		✓	
23. The procedures and materials for the assessment of my child must not be racially, culturally, or sexually biased.	✓		
24. If my child is placed in a regular classroom a resource specialist shall be assigned to my child for a majority of the schoolday.		✓	
25. My child's individualized educational program must be reviewed at least once a year.	✓		
26. If my child is placed in a regular classroom for a majority of the school day, it is the responsibility of the classroom teacher to coordinate all special services provided my child.		✓	
27. The evaluation of my child must be done by school district employees.		✓	
28. If a school district cannot provide the school program my child needs, the school district will pay for private school placement.	✓		
29. Once a hearing is held on any complaints I may have, I may not appeal further.		✓	
30. The school district is required to place my child in a class where there are children with similar disabilities.		✓	
31. My child's program placement must be re-evaluated every year.		✓	
32. If appropriate, special educational services may include room and board and transportation services if specified in my child's individualized educational program (IEP).	✓		
33. The schools may withhold certain results from my child's evaluation if the information is highly technical.		✓	

	TRUE	FALSE	DON'T KNOW
34. An individualized educational program must be developed within 35 days after I give my consent for the assessment.	✓		
35. My child may attend the meeting designed to develop the individualized educational program for him or her.	✓		
36. My child's educational program must provide a diagnostic label indicating the type of disability my child has.		✓	
37. If a district refuses to change part of my child's school record which I believe to be inaccurate, I have the right to a hearing.	✓		
38. I must give my written consent before my child may be evaluated for special services.	✓		
39. I must be informed of the evaluation procedures to be used and the tests to be used in evaluating my child.	✓		
40. Any individual, public agency, or organization may file a written complaint with the Superintendent of Public Instruction or the superintendent of a local public education agency alleging a matter which, if true, would constitute a violation by that public education agency of federal or state law or regulation governing special education and related services.	✓		

PM/cd

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C. Awareness Presentations

Module 1 - Awareness Presentations: Same and Different

Level 1: Pre-School, Kindergarten, First Grade

Time: 30 minutes

Objectives:

- The participants will learn about the severely disabled students who attend their school.
- The participants will be able to identify several ways in which developmentally disabled people are the same as and different from themselves.

Materials:

- two combs
- two toothbrushes
- two spoons

Personnel: One discussion leader (may be special education staff, parent volunteer, regular education staff, resource person, or older student).

Activities:

1. Introduce yourself. State the goals of the presentation simply and briefly, and stop from time to time to check that the children understand you. For example, "We're going to talk about some new kids in your school. They are disabled. Can you say disabled? That means that some of them can't see, or talk, or walk the same way you do. What does disabled mean?" (students answer)

2. Quickly ascertain students' comprehension of the concept "same" and "different". If their understanding is shaky, teach the concepts as follows.

    a. Teach same. Display two matching objects. Tell the children that "we say these are the same." Display two other matching objects. Ask if they are the same. Elicit group oral response. Continue until responses are correct.

    b. Teach different. Display two mismatched objects. Tell the children that "we say these are different." Display two other mismatched objects. Ask if they're different. Elicit group oral responses and continue until responses are correct.

c. Present pairs of objects at random, some matched, some mismatched. Ask "what are these, same or different" and elicit group oral responses until firm.

3. State that people can be the same and people can be different.

   a. Show a picture of a child with physical disabilities. Say, "this girl is different from some of us. She uses a walker to get around. She is disabled. What are some other ways she's different?" (e.g., hair color, wears protective helmet).

   b. Say, "but this girl is the same as we are in lots of ways. She likes to play, she has friends..." Elicit other ways students with disabilities are the same as nondisabled students (e.g., have parents, learn in school, get mad sometimes).

4. Leave time for questions and discussion about the severely disabled students in the children's school. Ask if they've met any of the severely disabled students in the playground or in the hall.

Follow-up suggestions:

1. Schedule a disabled visitor from the community.
2. Leave pictures of people with disabilities with the classroom teacher so that the children can view and discuss them again the next day.
3. Make an "experience chart". Children can dictate questions and statements about "people who are different".
4. Draw same and different pictures (this is difficult for kindergarten). Each child folds a large sheet of paper in half, draws someone 'the same as you" on one half, and "someone different from you" on the other half. Staff moves around the room as children draw, eliciting children's explanations of the drawing, and writing these verbatim on the drawings.

Module 1

Level 2: Older Students (Elementary, Middle, High School)

Time: 45 minutes

Objectives:

- The participants will know that there are disabled students who attend their school.
- The participants will use appropriate vocabulary to describe developmental disabilities.
- The participants will identify ways in which developmentally disabled persons are like and unlike themselves.

Materials:

- Short film: Harold or Paige (Encyclopedia Britannica) or Keep on Walking (March of Dimes) or David (Film Maker's Library) (see Chapter 8)
- Blackboard or overhead projector

Personnel:

One discussion leader (May be special education staff, parent volunteer, regular education staff, resource person, student leader. We strongly recommend participation by a peer tutor if available.)

Activities:*

1. Introduce self. Introduce peer tutors or special friends if present. Write the objectives of the presentation on board. Explain that the severely disabled students attend classes taught by special education teachers, but that they will be in the lunchroom, halls, yard, etc., with everybody else.

2. List vocabulary words used to describe disabilities and disabled persons on the board.

   a. List inappropriate words (four eyes, retard, etc.). List these first, asking students to supply them (if they can't, suggest some). Eliciting these terms first clears the air and provides a good opening for later dialogue. Elicit terms used to describe less extreme "disabilities" such as "fatso" or "metal mouth". Make the point that none of us is perfect -- we all have disabilities of some sort.

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* Based on an activity described in Nietupski, et al., 1980.

b. List some appropriate words by asking students, "What do you call somebody who can't hear?" Besides eliciting the appropriate terms for various disabilities (e.g., deaf, mentally retarded), see if the students are aware of the distinction between disability (the limitation imposed by a physical or mental impairment) and handicap (the limitations imposed by society's reaction to disability). One of the slogans of the National Association for Retarded Citizens is "Your attitude is my biggest handicap".

3. Get ready to show the film. Since we have yet to find a short, suitable film dealing with severely or multiply disabled people, we first use one of the three films listed to start discussion on disabilities. Later, we talk about multiple impairments. We attempt to match the age of the audience members to the age of the central character in the film. David is most appropriate for high school/middle school audiences; Harold is appropriate for upper elementary and middle school, and Keep on Walking and Paige for elementary school.

   a. Introduce film. Ask students to look for ways in which the star of the film is like and unlike themselves.

      1) Harold is blind; he attends a regular middle school in San Francisco. He is shown in school and in the community.

      2) Paige has Down's syndrome. She attends a regular elementary school. Her story is told by Paige's nondisabled sister.

      3) Marty Mimmack (Keep on Walking) was born with a physical disability -- he doesn't have arms. He attends a regular school, and is shown answering questions from an elementary school class.

      4) David is a young adult with Down's syndrome. He is an extremely capable individual and is an outstanding model showing what a mentaly retarded person *can* do.

   b. After viewing the film, discuss it.

      1) How is the central character different from many of us? (e.g., special aids used, speech (Paige), ways of getting around).

2) How is the central character like us? (e.g., likes to have fun, has same needs for survival, has family and friends, is learning similar things).

3) Could you be friends with (would you hang out with) Harold, Paige, David, or Marty? Do you know anyone with a disability?

4. <u>Allow time for questions and discussion about the classes of severely handicapped students in the student's own school</u>.

Follow-up suggestions:

1. Add appropriate disability words to students' vocabulary/spelling lists.
2. Place a question box in the room, and ask all students to write (or dictate) at least one question. Answers can be given at the next presentation. These questions can provide excellent feedback to discussion leaders. They also allow students to express themselves openly.
3. Schedule a disabled guest speaker from the community.
4. Begin a journal, writing booklet, or collection of drawings related to disabilities.

Module 2 - Learning Stations 1, 2 and 3: Vision, Communication and Locomotion

Level: Suits second grade through adults with minor modifications in language and pacing.

Locomotion

This module is a disability simulation -- it shows participants how disabled people can compensate for their physical limitations through the use of alternate sensory modalities, prosthetic devices, and communication systems. Participants also engage in values clarification through role-playing.

At the beginning of the period, participants are divided into groups. Each group rotates through the learning stations. After all stations have been completed by each group, the participants join together in a summary discussion.

Time: 45 minutes for the whole module; seven to 10 minutes for each section.

Personnel: one adult and/or two peer tutors per station.

Vision Station

Objectives:

- Participants will identify objects by using senses other than vision.
- Participants will brainstorm ways of assisting blind students.

Materials:

- blindfolds
- pencil and paper for each participant
- items to stimulate the other four senses. Examples are: smell - lemon rind, rubber eraser, pickle, chocolate bar; taste - raisin, nut, small pieces of candy, small pieces of orange or lemon peel; touch - small calculator, tape measure, seashell; hearing - bell, zipper, music box.

Activities:

1. Name the five senses. Ask what disability a person has who has limited vision. Tell students that some of the students in the severely disabled class are blind. Ask if participants would like to experience

being blind. Tell them that this will involve being blindfolded for about 10 minutes. Tell participants that no tricks will be played on them and that if they feel uncomfortable they may sit out and observe. Explain to younger students that they should raise their hands when they know what the item is that they're sensing. When everyone has had a turn, tap someone on the shoulder to identify the object.

2. Blindfold participants.

3. Take one item from each sense area (i.e., a raisin for tasting, a bell for hearing, etc.) and present it to each participant. Tell younger students to remain silent until you let them know that each has a single item. Then have them take turns identifying the objects verbally. Older students should write down the names of the items as they're presented, as best they can. By the end of the activity, make sure that each student has had a chance to experience all four sense areas.

4. When all items have been presented, have participants remove their blindfolds. Ask how they felt during the activity. Stress the ways blind people can compensate for loss of vision with other senses. Ask older students how they felt writing their responses while blindfolded. Emphasize the fact that the participants learned by using other senses than vision. Ask participants to name the senses they used in this activity.

5. Discuss the ways a blind, severely disabled student could function in this school. If a special friend/peer tutor is present, he or she could help participants brainstorm ways to make the building and classroom more accessible -- i.e., tactile cues help identify the room, scent and sound help identify the cafeteria, keeping classroom furniture arrangement constant helps the student avoid obstacles.

Communication Station

Objectives:

- Participants will be able to name and give an example of several verbal and nonverbal communication systems used by most people.
- Participants will be able to communicate by using alternative communication systems, a communication board, a picture communication booklet, gestures, and sign language.

Materials:

- a communication board
- a picture communication booklet
- three large pictures: a food item, a baby, and a television set.

Activities:

1. Ask, "how do we communicate?" Elicit examples from participants: speech, hearing, writing, facial expressions, pictures (i.e., international road signs), gestures, signals (i.e., football referee).

2. Ask, "how do severely disabled people communicate?" Elicit examples from participants. The special friend/peer tutor can give specific examples from this school (e.g., facial expression, vocalization, communication board, picture booklets, sign language).

3. Identify pictures without words. Ask for volunteer who will describe something they see without talking. Show one picture to one participant without letting others in the group see the picture. Have him or her act out what he or she sees. (This activity is similar to the game, charades.) Present all three pictures to three volunteers in order of increasing difficulty (i.e., candy, baby, t.v.). When the pictures have been identified, point out that the task would have been easier if the students had some knowledge of a shared communication system.

4. Use the communication board and booklet. Explain how a communication board works. Demonstrate a brief message -- e.g., I want a drink. Allow participants to use the board and booklet to communicate messages to each other.

5. Teach five specific signs used by severely disabled students in this school. Teach them imitatively ("do what I do"), the expressively ("sign hi"), then receptively ("what does this sign mean?"). We choose signs that are likely to be used in play- ground, hallway, or cafeteria interactions, such as hi, bye, eat, play, and drink.

Locomotion Station

Objectives:

- Participants will be able to state several wheelchair safety rules.

- Participants will be able to identify several communication courtesies.
- Participants will be able to name several problems encountered by wheelchair and walker users.

Materials:

- At least two wheelchairs -- one athletic model, one standard
- walker, sling-walker, or whatever locomotion devices are used in your school
- three traffic cones to set up an obstacle course.

Activities:

1. Wheelchair safety demonstration.
   a. Always make sure that the brakes are on when getting in or out of the chair.
   b. Always put the brakes on when the wheelchair is "parked".
   c. Release both brakes before trying to move the chair.
   d. Hands should be placed on the steel rims of the wheels rather than on the tires.
   e. Demonstrate how to move the wheels for turning right, left, and making 180° turns.
2. Allow students to take turns running the obstacle course, using wheelchairs and walkers. An alternative to setting up an obstacle course is to use naturally-occurring school obstacles. Students can be directed to cross the room, get a book from the bookcase, go in and out of the classroom doorways, go to the water fountain.
   a. While some students are using the equipment, discuss with others the problems of access in their school. For example, can a person using a wheelchair reach water fountains, cafeteria counters, etc.? How accessible is the yard, the auditorium, the office? How could difficult-to-reach areas be made accessible?

3. Role-play communication courtesy problems.

   a. Two students talk about a person in a wheelchair. How does it feel to be treated as though you weren't present?

   b. One student pushes another without talking. How does it feel to be treated as if you were helpless and passive?

   c. Push a student in a wheelchair and "park" the chair so that the student is facing a wall or away from others. How does spatial arrangement affect communication?

4. Summarize the above activities with courtesy suggestions elicited from students: i.e., always talk to and not about severely disabled students; always talk to a severely disabled person you're assisting. Ask him or her if he or she wants help. If they can't communicate, ask a teacher or use common courtesy -- let them see who you are. Tell them what's going on. Find out where they'd like to go. Walk and push chairs at a normal walking pace; park wheelchairs so that people in chairs are facing others. Put yourself in their place and treat them as you'd like to be treated.

General Group Discussion (to be conducted after all participants have gone through the three learning stations)

1. How did you feel as you went through the stations? Were any activities particularly difficult? Why?
2. What did you learn from these activities? How are people with disabilities the same as nondisabled people?
3. Will you act differently toward the next disabled person you meet? If so, what will you do differently?
4. How did these activities affect the way you feel about the severely disabled students in your school?
5. Leave time for questions about the severely disabled students' particular needs.

Follow-up suggestions:

1. Complete the "Could You Still?" form from the KIDS Project. (See Chapter 5, Module 6)

2. Perform an accessibility survey. Use the "Could Tracy Get Around Your School" form from LINC Services. Students work in pairs to check out school building and/or community sites.

3. Continue to add to the journal or the booklet on disability awareness. Students can write or draw their reactions to the learning stations. For example, choose one station, describe your feelings as you went through the activities, tell how you are like and unlike a person with that disabilty, list things to remember when interacting with a disabled person.

Module 3 - Learning Stations 4 and 5: Mental Retardation and Disability Aids as Tools

Level: Suits second grade through adult with minor modifications in language and pacing.

This module is a disability simulation - it shows participants how disabled people can compensate for their physical limitations through the use of alternate sensory modalities, prosthetic devices and communication systems. Participants also engage in values clarification through role-playing.

(At the beginning of the period, participants are divided into groups. Each group rotates through the learning stations. After all stations have been completed by each group, the participants join together in a summary discussion.)

Time: 45 minutes for the whole module; 10 to 15 minutes for each station.

Personnel: one adult and/or two peer tutors per station.

Mental Retardation Station

Objectives:

- Participants will be able to state how they feel after experiencing the results of failing to meet our cultural norms for "smartness" and speed.
- Participants will be able to state several ways in which cues/task analysis help us learn.

Activities:

1. Intelligence Test

Materials:

- 15 small objects (we use plastic animals, dollhouse furniture, etc.)
- paper and pencil for all participants
- paper to cover the small objects.

a. Pass out paper and pencil. Tell people that you are going to test them to see how smart they are. Tell them you want them to write down all the objects you show them.

Test 1 - Put objects in a pile. Give them at least 15 objects. Give people five seconds to look at objects. Cover the objects. Tell them to write down all the items they saw.

Test 2 - Take away five objects. Make sure they are not in a pile. Only give them five seconds to look at the objects. Cover the objects. Tell them to write down what they saw.

Test 3 - Show people seven objects. Give them 10 seconds to see the objects. Tell them to write down what they saw.

b. Ask, "How did you feel when I gave test 1? What about test 2? How did I make the test easier? Was it a fair test?" Ask questions 2, 3, 5, 6, 7 of the puzzle activity. (see the following pages)

2. Cues/Task Analysis

Materials:

- one plain puzzle for each person
- a puzzle with a picture on it for each person
- a pattern of a puzzle.

a. Give each participant a plain puzzle. Tell them that this is a test to assess how smart they are. Tell them they have two minutes in which to do the activity. While they're doing the puzzle, tell them how slow they are or say things like "Aren't you finished? What's the matter with you, you're certainly not as bright as the other group", etc.

b. When the time is up, give them the puzzle with the cut-up picture on it. Continue to give them a hard time about being slow. Give them two minutes to work on the puzzle. If they still can't complete the puzzle, show them the uncut pattern of the puzzle.

c. Ask, 1) "How did you feel while I was calling you names? 2) How would you feel if you had this kind of pressure on you all the time? 3) How might you act or feel? 4) How did I make the activity easier? 5) Do you see any relationship between this activity and how people who are mentally retarded may feel or act? 6) What can you do to help people who are mentally retarded learn activities or tasks? 7) Can mentally retarded people learn?

Disability Aids as Tools Station*

Objectives:

- Participants will be able to name some tools that we all use. Prosthetic aids are just another sort of tool.
- Participants will experience physical disabilities and will use disability aids employed by disabled persons.

Materials: canned peaches or other food to sample

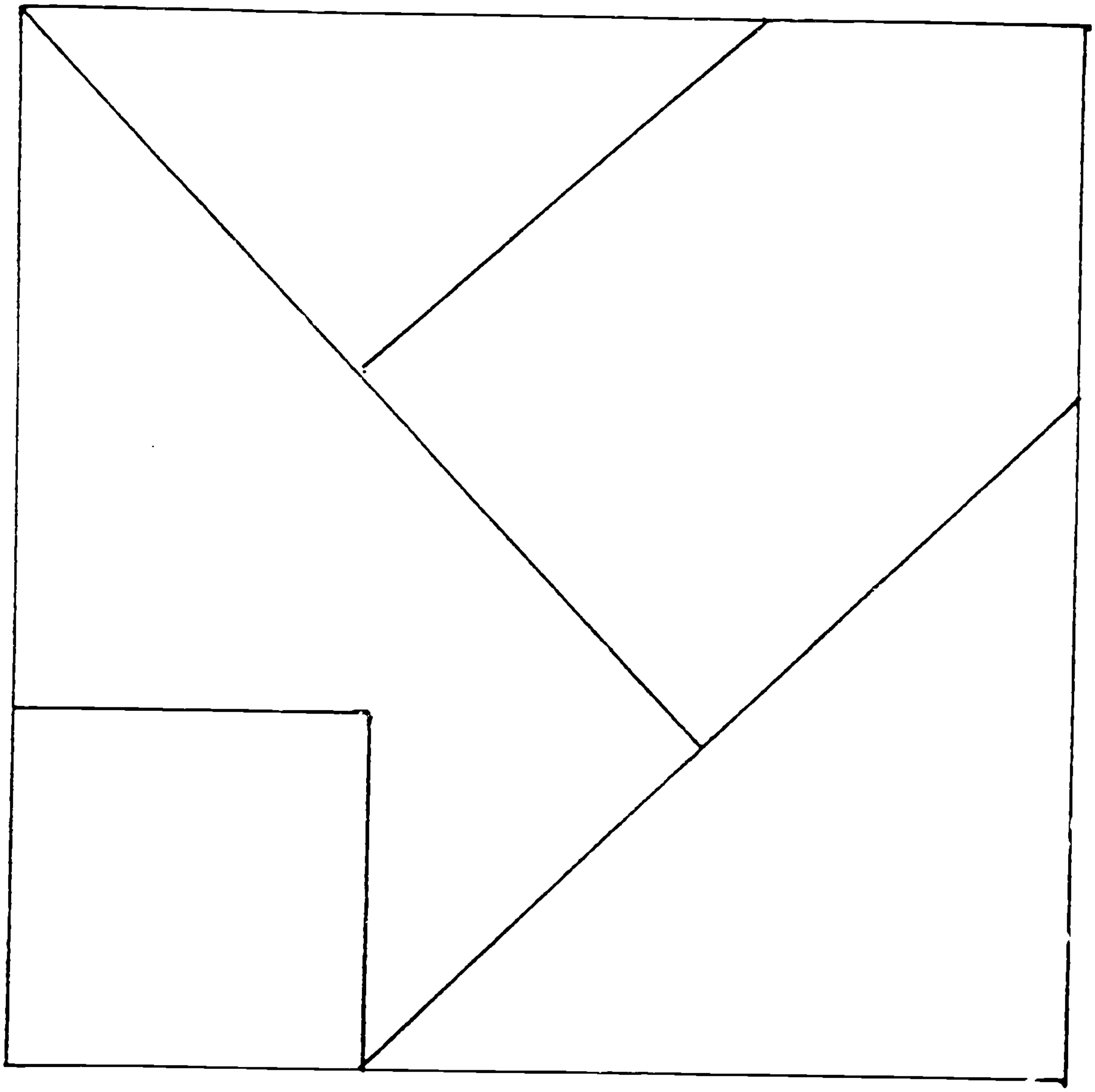
- spoon aids and spoons
- standard plates or bowl
- bowl with shaped side
- masking tape
- scoop plate
- cutaway cup
- regular cup
- nonslip mat
- hammer
- universal cuff
- bottle opener
- ties to bandage arms for range limitation
- ruler
- basket or bag large enough to hold/conceal all of the above tools

Activities:

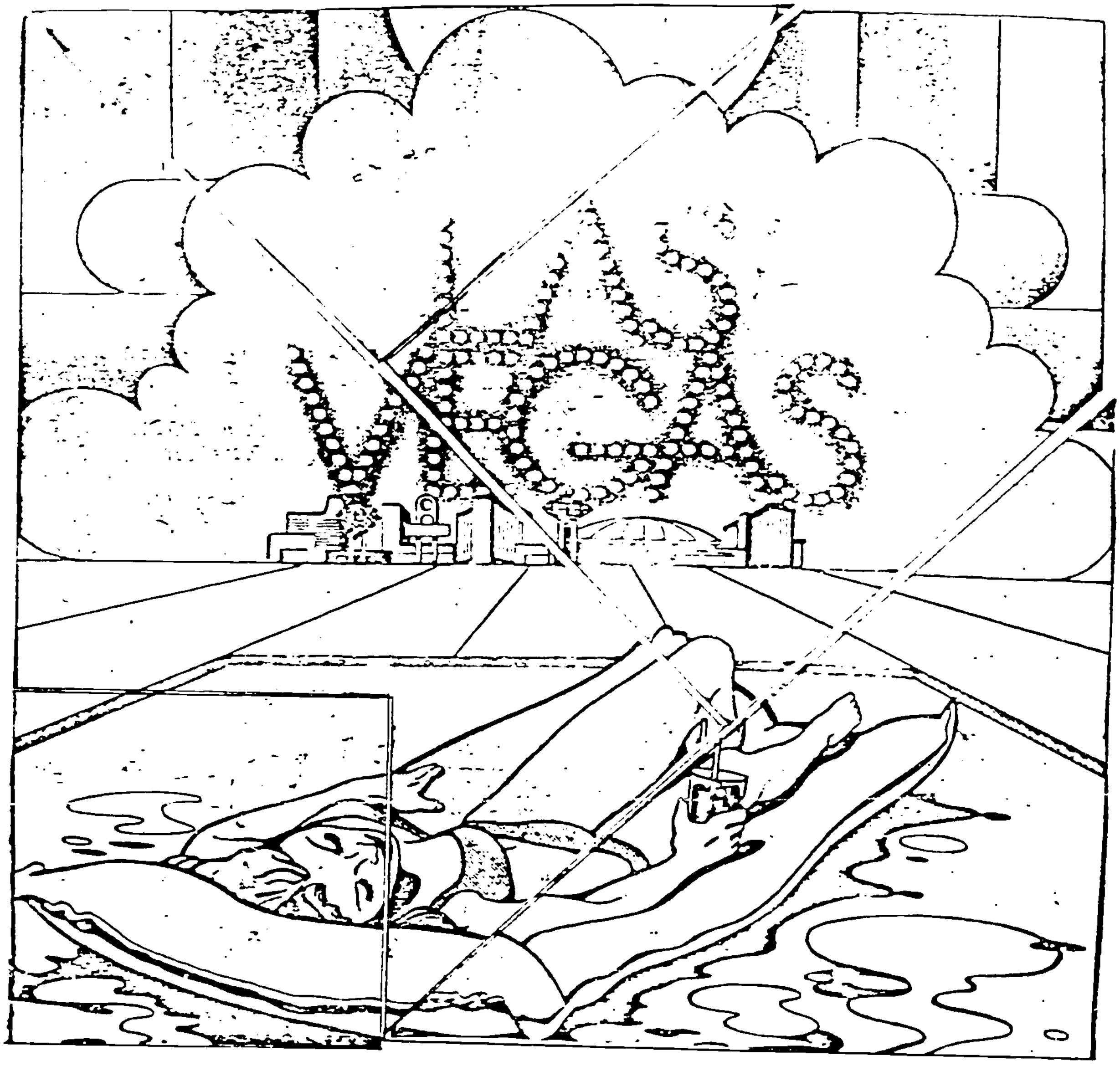
1. Introduce yourself. Rummage dramatically in bag. Produce, in succession, a hammer, ruler, bottle opener. Say, "what does this do?" as you produce each one. Say, "what do these things have in common?" (They're all tools -- they help us work more easily and efficiently.) Say, "we're going to look at tools some disabled persons use."
2. Ask for a volunteer. Tape the volunteer's fingers together. Explain that many severely disabled persons have muscular problems that restrict their use of their limbs. Other participants watch while the volunteer tries to eat from a regular dish, using an unadapted spoon. Show how a nonslip mat can help.
3. Produce spoon aids, a universal cuff and a shaped bowl. Allow the volunteer to try using these "tools". Explain that the spoon aid is used to hold the spoon level to avoid spilling. Point out that everyone likes to be independent. Demonstrate the use of a universal cuff as an aid to holding the spoon

* Suggested by an activity in Voeltz, Special Friends Trainer's Manual (see References)

ANSWER TO PUZZLE TASK



Puzzle With Picture Cue



4. Ask for another volunteer. Have her try to drink from an ordinary cup/glass with her head bent forward as a person does who has difficulties with head control. Produce a cutout cup. Let the volunteer try this.

5. Discussion: How did the volunteers feel with others watching them? How can tasks be changed so that people with disabilities can be independent? What other special "tools" have you seen used by disabled people?

General Group Discussion (to be conducted after everyone goes through both learning stations)

1. How did you feel as you went through the stations? Were any activities particularly difficult? Why?

2. What did you learn from these activities? How are people with disabilities the same as non-disabled people?

3. Will you act differently towards the next disabled person you meet? If so, what will you do differently?

4. How did these activities affect the way you feel about the severely disabled students in your school?

5. Leave time for questions about the severely disabled students' particular needs.

Follow-up Suggestions

1. Schedule a disabled guest speaker from the community.

2. View films from the People You'd Like to Know series, Encyclopedia Britannica.

3. Add to a journal or booklet on Disability Awareness. Students may write or draw their reactions to one of the stations: describe their feelings, tell how they are like or unlike a person with that disability, list things to remember when interacting with a disabled person.

4 Imagine you are teaching visitors from another culture to use our American money. What cue/clues could you give them to help them use our system? Write a task analysis to help them. In other words, list the cues you would use to discriminate coins and bills.

5. Ask students to invent/develop a disability aid. Have students present their products to the class.

Module 4 - Civil Rights and Disabled People (this lesson can be incorporated into a social studies curriculum)

Level: 5th grade on up

Time: 45 minutes

Objectives:

- Participants will be able to discuss the past and present rights of disabled people as guaranteed by PL 94-142 and Section 504 of the Rehabilitation Act.
- Participants will be able to define the meaning of equal and discriminatory education.
- Participants will be able to discriminate between normalized and nonnormalized treatment.

Materials:

- Overhead projector
- Transparency of cartoon showing the steps up to a building. (see p. 145)
- Transparency: Could Tracy Get Around Your School? (see p. 144)
- Transparency: David (see p. 146)
- Transparency listing the six principles of PL 94-142.

1. Zero reject
2. Nondiscriminatory assessment
3. Individual Education Plans

4. Least Restrictive Environment
6. Due Process
6. Parent Participation

Personnel: one discussion leader

Activities:

(Note: Module 4 deals with a complex issue. We offer more activities here than can be completed in a 45 minute period. Choose those activities that will best suit your audience.)

1. Discussion: Project the cartoon illustrating lack of access. State, "in the past, disabled people had different civil rights than nondisabled people. For example, if there were architectural barriers in the

neighborhood public school, or at their job site, that was just 'too bad' for the disabled person." Ask participants to give examples of other barriers they or their families may have experienced (e.g., attitudinal, linguistic, physical).

2. <u>Discussion: Public Law 94-142 - 'Education for All Handicapped Children Act,' passed in 1975 - and section 504 regulations of the Rehabilitation Act, passed in 1977.</u> Both laws make it illegal to discriminate against people on the basis of disability. Project "Tracy" transparency. These laws are modeled on civil rights legislation originally written to protect the rights of racial minorities. They guarantee an equal, free, and appropriate education for all disabled children. It is because of these laws that the class of children with severe disabilities are attending public schools. Does your school have architectural barriers that discriminate against people like Tracy?

3. <u>Glurks and Whees.</u> Imagine that you live in another country. There are two kinds of people in this country - the glurks and the whees. The glurks walk on two feet, use speech to communicate; the whees ride in golfcarts and use sign language. Imagine that you are ______________________ (insert name of school administrator) and you have to decide which students will come to your school. Tell whether the following statements are fair or unfair ways of deciding:

   a. Most of the people in this neighborhood are whees. If a student is too glurky, he should not go to our neighborhood school.

   b. The teachers and I speak the whee language. Our school admission tests are given in whee. If a student doesn't speak whee, she shouldn't go to our school.

   c. Our school teaches the things whees need to know in order to be successful in later life. We teach the same way to everybody. If the glurks don't like it, too bad.

   d. We have two kinds of schools -- schools for whees and schools for glurks. If you're a whee, you go to a whee school. If you're a glurk, you go to a glurk school.

   e. Once we've decided whether you're a whee or a glurk, you keep that label forever.

f. We are experts at our school. We know what's best for whees and glurks. If you or your parents don't agree with what we decide is best for you, too bad.

Would you like to live in that country? Why or why not? Display the list of six principles of PL 94-142. Explain the six principles as they relate to the previous decision.

4. Normalization. State, "sometimes, people who mean well treat disabled people as though they weren't people. They stereotype them. They react to the disability rather than to the person and treat disabled people differently from others. This is not normal treatment." Display transparency of page 13 of Dignity booklet. (see p. 147) Cover the lower paragraph. Have students read the upper paragraph. Ask, "did the doctor treat Bill normally? Why or why not?" After students give their reactions, uncover the lower paragraph. Let them read it. Ask, "how could Dr. Goodman have normalized his speech ? Do we treat students with severe disabilities 'normally' in this school? Why or why not?" If there's time, use the same format to view additional transparencies from Regional Rehabilitation Research Institute booklets (e.g., p. 14, in Dignity on equal access to education) which are available from the Regional Rehabilitation Research Institute, The George Washington University, Washington, DC 20052.

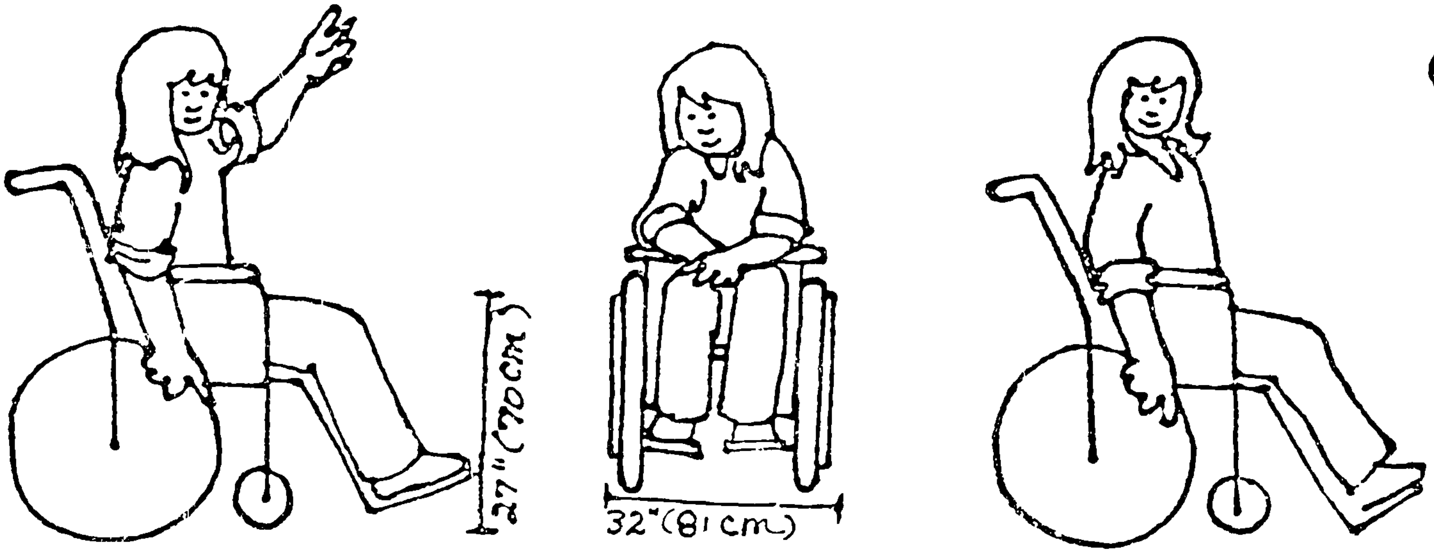
Follow-up:

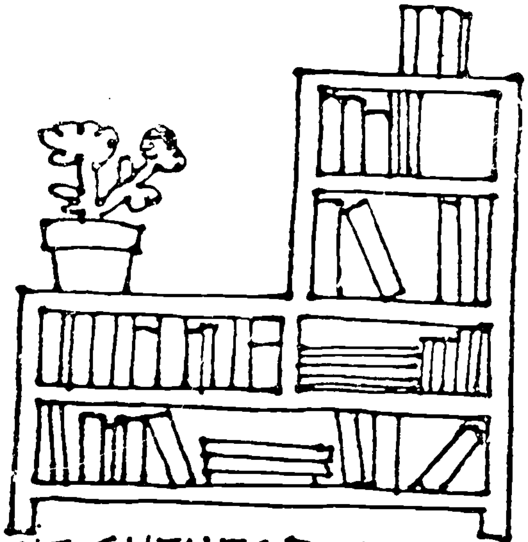
1. View a film on normalization. See David (a teenager with a developmental disability narrates and acts) or A Day in the Life of Bonnie Consolo (a woman who was born without arms is followed through a day in her life).

2. Using the example on the next page - Could Tracy get around your School? - participants work in pairs to assess the school's or community's accessibility.

3. Read and review a story for its "nonnormalized" elements (e.g., the disabled character always being sicker, weaker, younger). Use "Stamp Out Handicapism in Books" as a guide (see attached example). Use the examples on the following pages to stimulate discussion.

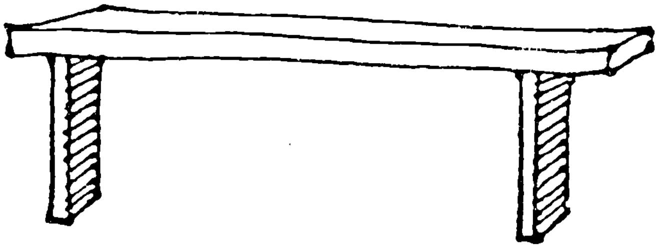
Could Tracy Get Around Your School?



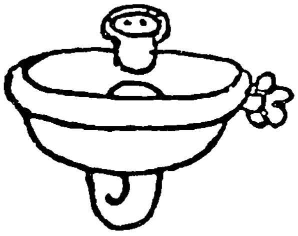


CAN THE SHELVES BE REACHED?

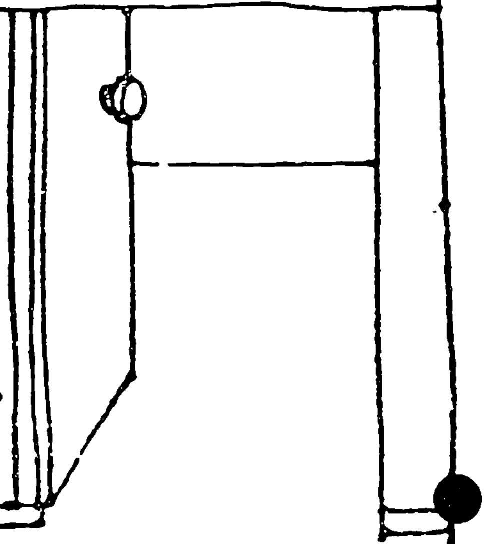
ARE THE TABLES TOO LOW?



CAN THE WATER FOUNTAIN BE REACHED?



ARE THE
DOORWAYS
TOO NARROW?



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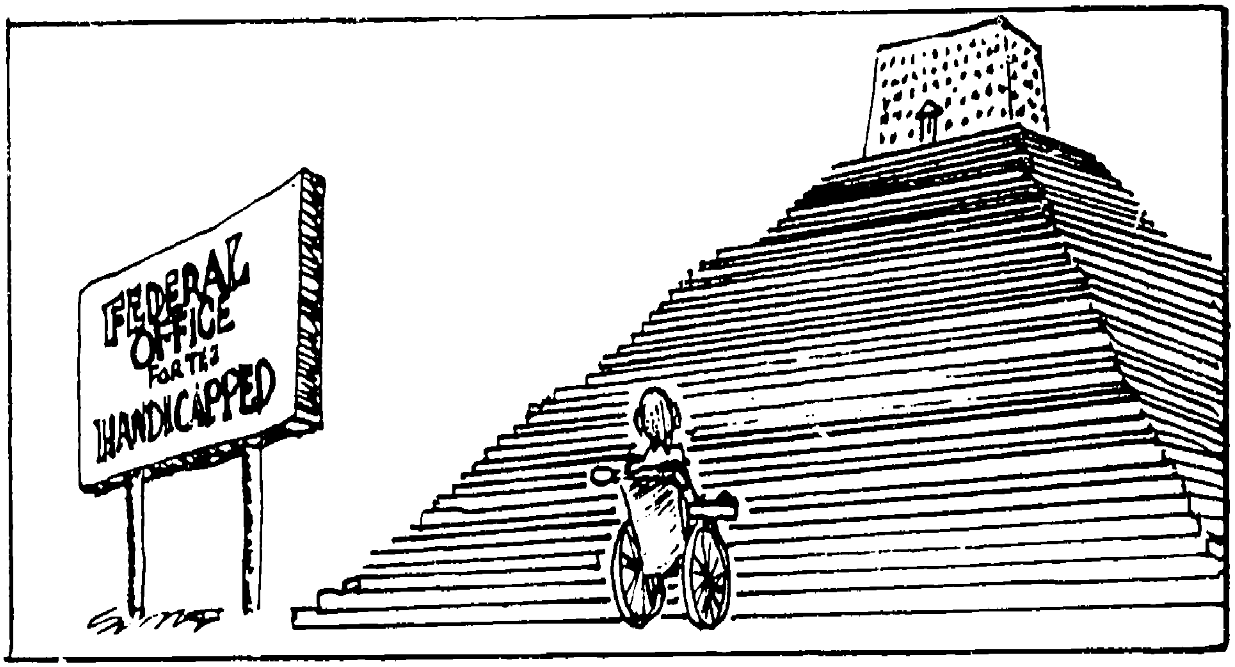
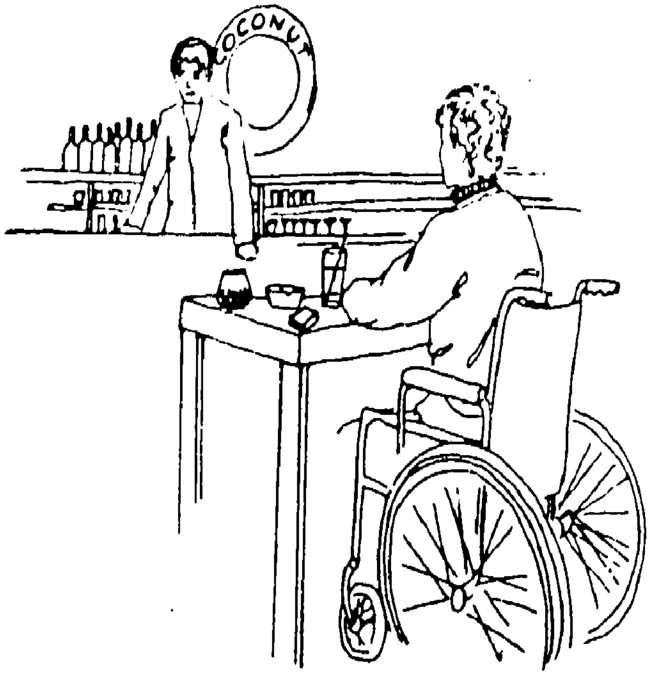

FEDERAL OFFICE FOR THE HANDICAPPED

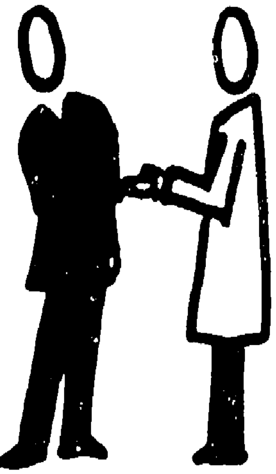
From <u>The invisible battle: Attitudes toward disability</u>. Regional Rehabilitation Research Institute, Washington, DC.

David has been an occasional patron of The Coconut, a bar and discotheque, where he goes to socialize and meet potential dates. David, who uses a wheelchair, asks The Coconut's owner to build a ramp so that he can get in and out unassisted. The owner refuses, telling David that he should come to the bar with a friend or, if that's impossible, that any of The Coconut's management staff would be willing to help David inside.



Many of you may feel that The Coconut's owner is being very reasonable in his attitude toward David's patronage and that his offer of help is a generous one. The owner's logic is that the management staff is already paid to accommodate the customers, and the cost of a ramp is probably prohibitive. But what does the prospect of being accompanied and carried in and out do for David's independence and the image of him that is presented to the other customers? Being constantly aided depicts David as being helpless and sets him apart from the other customers, immediately upon his entrance to the bar. David has finally worked through his own fear of appearing alone in public, only to find that wherever he goes he must submit to being treated differently—his disability being the first thing people notice. In fact, the cost of a ramp is usually quite low or the use of another accessible entrance is usually not prohibitive. The costs involved are small in comparison to David's loss of self-esteem and in terms of the extra business generated by The Coconut's accessibility. A facility which is accessible to disabled persons is more usable by *all* persons.

From Dignity. Regional Rehabilitation Research Institute, Washington, DC.



Mr. Bill Todd is a twenty-eight year old person with Down's Syndrome. He is not feeling well and decides to call his doctor. Dr. Goodman says, "Billy, come into my office. Be a good boy and we will see what's the matter with you."

Mr. Todd is hurt and angry. He does not like being called Billy or being considered a "good boy." He thinks of himself as a man. He works, lives in an apartment, and has a girl friend. He doesn't enjoy being treated or talked to like a child. He wishes Dr. Goodman would treat him just like any other patient. Mr. Todd can't understand why he is called "Billy," while every other man is called "Mr." in the doctor's office.

Module 5: Growing Up With A Disability

Level: upper elementary school and up

Time: 45 minutes

Objectives:

- Participants will be able to restate several points that a disabled guest speaker has made.
- Participants will be able to name several new ideas about what life is like when a person has a disability.

Materials:

- "Could You Still" - handout

Personnel: one discussion facilitator, one disabled guest speaker

Preparation:*

Before the session, meet with and provide an orientation for the guest speaker(s). Jointly develop the session with the guests so that the personal sharing is comfortable and the particular talents or interests of each guest are incorporated into the session. As part of the orientation, encourage the guest speakers to think about the following topics that can be included in their presentation:

1. what special interest they have
2. what kind of work they do
3. something positive about their disability
4. how their disabilities have affected their lives
5. mobility techniques they use - including a description of the equipment that's necessary (wheelchairs, walkers, braces, etc.)
6. adaptive equipment they use (adaptive eating equipment, mouthstick, etc.)
7. what was it like growing up?

Activities:

1. Introduce your guest. Ask him or her to speak to the class for about 10 minutes, covering the points discussed in the orientation session. After the guest has spoken, allow the participants to ask questions.

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* From the KIDS Project Manual, Berkeley, CA. The Center for Independent Living.

2. Pass out the "Could You Still" handout. Have each student complete one copy. After all have finished, ask the guest speaker to help you discuss the students' reactions to the exercise. Ask individual students to give examples of things they think they couldn't do, and ask them to explain why. Were there any surprises in filling out the form?

Could You Still????

If you were (had):

	blind	deaf	physically disabled	retarded	learning disabled	emotionally disabled	epileptic	diabetic	sickle cell	ostomate	kidney disease	cancer
play ball												
kiss a friend												
eat ice cream												
fly a kite												
sing a song												
love a pet												
watch TV												
go on a picnic												
dance												
love your famil												
swim												
get married												
go to a movie												
be a parent												
play an instrume												
dress yourself												
live alone												
go to a party												
have a job												

y-yes
n- no

Module 6 - Labels and Myths

Level: Upper elementary

Time: 45 minutes

Objectives

- Participants will be able to list new and old terms used to describe disabilities.
- Participants will be able to use the appropriate terminology approved by people with disabilities.
- Participants will recognize that people with disabilities are people first, and disabled second.

Personnel: one discussion leader

Materials:

- four 8 x 10" label cards with strings attached
- blackboard
- overhead projector
- biography statements (see the last pages of this module)
- transparency of page 11, The Invisible Battle by Regional Rehabilitation Research Institute (see the References)

Activities:

1. Discussion: "Many labels have a history"

   a. Before the 19th century, anyone who looked or acted different was believed to be possessed by an evil spirit; they were said to be witches or insane.

   b. In the 19th century, Europeans interested in the biological sciences tried to institute a more specialized classification system. An idiot had an I.Q. of 25; an imbecile, an I.Q. of 49; a moron, an I.Q. of 74. Sometimes these classifications served racist or political ends; e.g., Mongolism (see S.J. Gould's essay on "Dr. Down's Syndrome" in The Panda's Thumb).

   c. What other labels have you heard used to describe people who are "different"?

2. Labeling Activity.* State, "the trouble with labels is prejudice. The word prejudice comes from pre-judgment. Labels are summary statements. They carry prejudgments about people." Ask for four volunteers from the group. Each is given a biography statement to read silently. One at a time, each volunteer stands before the group, wearing a label - i.e., deaf, blind, physically disabled, mentally retarded. While the volunteer is standing, group members call out/free associate the characteristics they associate with that label. Group members must look at the label-wearer while they speak out. The discussion leader should record their pre-judgments on the blackboard or overhead. After all disabilities have been characterized, the volunteers summarize their individual biographies for the group. The discussion leader should ask these volunteers to describe their feelings during the labeling exercise. State, "those labels reflect the fact that doctors and special educators used to specialize in treating organic problems in isolation. The social and economic consequences of organic problems were given little attention."

3. Summary. State, "now, people with disabilities are asking us to change the way we talk about disabilities. The World Health Organization has decided to change its terminology. Instead of focusing on medical problems or historical labels, people around the world are recognizing that people with disabilities are, first of all, people. Therefore, the approved terminology is:

   impairment = any loss or abnormality of physical or psychological structure or function.

   disability = restriction or lack of ability to function because of impairment.

   handicap = restriction or lack of ability to function caused by society's response to disability.

4. View the "David" transparency on page 11 of The Invisible Battle (see p. 146). Cover the right hand paragraph, and ask the students to read the left hand paragraph. Ask the students, "What is David's impairment?" (We can't tell, but apparently his legs are affected.) "What is his disability?" (His walking is restricted -- he uses a wheelchair.) "Is he handicapped?" (Yes -- the attitude of the bar manager and the architectural barriers in the bar handicap him.)

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* From the KIDS Project Manual

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Follow-up Suggestions:

1. Read a biography of a well-known person with a disability. Tell how he or she is like or unlike prejudgments made about people with his or her disability.

2. Pretend that President Reagan is deciding whether or not to allow children with disabilities to be integrated into public schools. Write him a letter telling him why students with severe disabilities <u>should</u> attend your school. Tell him how it benefits disabled and able-bodied students.

3. Add the new vocabulary words -- impairment, disability and handicap -- to your spelling list. Define each and give examples. E.g.,
    impairment - blurred vision
    disability - inability to read small print
    handicap - denial of a job in spite of qualifications

4. View the film <u>Feeling Free, Feeling Proud</u>. How were the actors in the film (people with developmental disabilities) affected by labeling?

<u>Biography Statements for Labelling Activity</u>

Biography of a Visually Disabled Person

My name is Elise. I can see light and dark, but not much else. I go to Elliot High School with a lot of people who don't have trouble seeing. My best subjects in school are English and Drama. I have two brothers, both younger than I am. I've never seen them, because I was born blind, but I can recognize their voices a mile off. I hope to go to Texas at Christmas to visit my grandmother. That will be my first time on an airplane.

Biography of a Physically Disabled Person

My name is Robert. I go to Roosevelt Middle School. I'm in a fifth grade class with twenty five other students. I get into trouble with my teacher sometimes for messy work and for talking to my best friend Mark. I was born with Spina Bifida. This means that the bones in my spine haven't closed around my spinal cord. I use a wheelchair to get around in school and in my neighbor- hood. At home I like to build model airplanes. I go to camp in the summer.

Biography of a Deaf Person

My name is April. I go to Susan B. Anthony School where I have a special resource teacher to help me with some of my school work. I wear a hearing aid, but it doesn't help me to hear everything. At home, I like to listen to the stereo through earphones with the volume turned way up. I use American Sign Language with my friends. My mother can't always understand what I say in Sign Language, and so sometimes it's like my friends and I know a secret code.

Biography of a Mentally Retarded Person

My name is Chris. I go to Adams Middle School. My hobbies are swimming and running. I have a sister who is in high school. Sometimes we go to McDonald's together. My best friend is Donna. She sits near me in school. Sometimes we work together in the cafeteria helping to make lunch. My favorite group is Devo.

5. Use the scenes in the *Dignity* booklet from Regional Rehabilitation Research Institute . Read each of the five "scenes" to your students and have them talk about them, as in Activity 4.

E. Films and Descriptions

The following list briefly describes films that can be used both for topical presentations to parent groups, and for training of community service providers or agencies. The majority of the descriptions were prepared by the Area Board V Developmental Disabilities at 1111 Jackson Street, Oakland (415-464-0439). Numbers 1-11 and 13-16 are available free for showing within the five-county San Francisco Bay Area (Alameda, Contra Costa, Marin, San Francisco, San Mateo). Names and addresses of film distributors are also included.

A DIFFERENT APPROACH

22 minutes

South Bay Mayor's Committee

Unique hire-the-disabled film that uses comedy to get its message across - namely, that disabled people are an untapped resource of capable employees. Written and directed by people from the All in the Family series, it employs a film-within-a-film technique parodying various marketing techniques. While the disabled and a number of celebrities perform all sorts of hijinks around the theme of the inner film, interpretation is offered by the young filmmaker, and the horrified committee who are seeing it for the first time.

Suggested audience: Employers, general public, employment counselors, service groups.

Recommended use: International Decade of the Disabled, employment development, service group meetings, in-service training for vocational counselors.

A MATTER OF EXPECTATIONS

30 minutes

James Stanfield Film Associates

This film emphasizes the practical issues involved in rearing the disabled child within the family and community setting. It emphasizes the need for parent, family, and community to work together to maximize the child's full potential. Stress is placed on physical, mental, and psychological stimulation. There are many practical suggestions for utilizing the latest knowledge and techniques in the fields of special education and child development. These are presented in a manner easy to understand and remember, even by persons dealing with these concepts for the first time.

Suggested audience: parents, professionals, medical society, nursing organizations and college students in early childhood education and social work.

Recommended use: workshops, parent organizations, in-service hospital orientation and college classroom use. (Suggested as a companion film to "What Was I Supposed To Do" and "Early Intervention")

COMING HOME

27 minutes

Stanfield House

Depicts the adjustments and training of a girl in her late teens who leaves a state institution to live at a residential "family life" home for the retarded. There she shares a "family life" with 11 other retarded young adults. She also begins a training program where use of community work and play resources are emphasized -- a program that recognizes her right to full citizenship and self-actualization. This is a film to promote public awareness and support of community-based programs for the retarded -- all those interested in the development of "family living" centers for the retarded can use Coming Home as a tool to educate and as a springboard for discussion.

Suggested audience: parents, professionals, high school & college students

Recommended use: workshops, inservice training, high school and college classroom use.

COUNT ME IN 20 minutes
The Stanfield House

Barry Sullivan narates this low-key picture of successful normalization of developmentally disabled citizens. Neighbors and employers of the disabled residents of small-group homes express their positive feelings about "mainstreaming". Good for stimulating discussion on true normalization.

Suggested audience: general public, parents, service organizations and board and care operators.

Recommended use: workshops for service organizations, parent organizations, general public education.

DAVID 29 minutes
Film Makers Library

An award winning Canadian film about David, a 16-year-old student with Down's syndrome. The film traces his parents' initial reaction to having a baby with Down's syndrome, their process of acceptance, and their insistence on providing David with the widest range of experiences, growth, and education. David, who has exceptional talents, is featured as the lead actor.

Suggested audiences: students -- jr. high and above, consumers, service groups, service providers, parents, social workers, teachers, P.T.A., infant development staff, physicians.

Recommended use: workshops and inservice training on mainstreaming, new parents' orientation.

I"M NOT WHAT YOU SEE 30 minutes
Film Maker's Libraries

An interview with Sondra Diamond, who was born with severe cerebral palsy and confined to a wheelchair, and who is presently a practicing psychologist. Ms. Diamond speaks of her childhood, her parents, and schooling, of prejudice both incidental and nearly fatal for her; of her ideas about "normality", "humanness", "beauty", personal morality, despair, sexuality, and human values.

Suggested audience: general public, professionals, consumers, college students, teachers, parent groups.

Recommended use: public education, consumer and parent groups, training and workshops for professionals, college classroom education.

IT'S A NEW DAY 9 minutes

South Bay Mayor's Committee

This is a film celebrating the new attitudes and technologies available to disabled people that can increase their integration into the mainstream of life.

Using an original song performed by singer/composer Danny Deardorff, the film highlights disabled people using new devices such as a vertical-lift wheelchair, talking calculator, Opticon-scan and Porta-printer. They are seen in diverse and challenging life styles, such as playing tennis and raquetball, dirt-biking, and performing such jobs as forest ranger, engineer, airline reservations agent, school teacher, and psychologist.

Suggested audience: service groups, employers, employment counselors, consumers, community groups, college students, teachers, veterans administration, civic leaders, equal access advocates, equal employment advocates, general pbulic.

Recommended use: inservice training, sensitivity training, workshops, vocational and pre-vocational counseling sessions.

THE KEY IS UNDERSTANDING 15 minutes

A training film to assist law enforcement, firemen, ambulance drivers, and bus drivers who encounter disabled people exercising their basic rights to be treated as productive human beings and as citizens who are entitled to full protection, rights, and privileges under the law. It shows situations involving people with mental retardation, blindness, cerebral palsy, epilepsy or other physical handicaps. "The Key is Understanding" provides concrete information about the disabled population but also has a broader and deeper message to share. While disabled people may be special in a few ways, they are like all people with the same needs to be loved, to feel worthwhile, to be treated with dignity and equality. This film shows viewers how to accomplish this important task. This film focuses on law enforcement but is valuable to other service providers as well.

Suggested audience: service providers, parents.

Recomended use: in-service training for fire departments, emergency service, police departments, bus drivers, and community workers.

NICKY: ONE OF MY BEST FRIENDS — 15 minutes

McGraw-Hill Films

"Mainstreaming" is the name of the broad-based atempt to integrate disabled youngsters into the public educaiton system in the United States. This film presents the case of an eleven-year-old boy with cerebral palsy participating in a classroom in Mamaroneck, New York. The film explores his relationship with other children and his teachers. NICKY shows the positive aspects of "mainstreaming" without ignoring the problems involved.

Suggested audience: children, age 12 and up; parents, teachers; professionals; college students.

Recommended use: teacher training; oreintation to mainstreaming; meetings; and discussion groups

ON BEING SEXUAL — 22 minutes

Stanfield House

In this documentary, parents and professionals talk about sexuality and the mentaly retarded. The film points out that mentally retarded people need to learn about their own sexuality. Sol Gordon, Ph.D., Professor of Family Studies, Syracuse University, talks with retarded young adults about sex. Winifred Kempton, MSW, Director of Education, Planned Parenthood of Southeastern PA, talks about the necessity of giving accurate, complete information.

Suggested audience: parents professionals, board and care operators, other community providers, sheltered workshop staff.

Recommended use: training for parent groups, board and care operators, teachers, sheltered workshop staff.

PEOPLE FIRST — 34 minutes

James Stanfield Film Associates

"We are people first and handicapped second." The most ambitious documentary ever produced on the subject of equal rights for the mentally retarded. This film was shot to document the lives and political activities of people first -- a self-advocacy group of disabled citizens.

Suggested audience: general public, consumers, prents, professionals, service and church groups, and board and care operators.

Recommended use: community groups, parent groups, consumer workshops, sheltered workshops, and in-service trianing for board and care operators.

PEOPLE YOU'D LIKE TO KNOW series

Encyclopedia Britannica Corporation (film: 10 movies with one introducing PL 94-142 and one on mental retardation)

THEY ALL CAN WORK

28 minutes

James Stanfield Film Associates

This film is about people who are learning to function in a society that doesn't always have time for them. A group of adults with physical and mental disabilities are employed by Natural Recovery Systems, a recycling factory located in Canada, where automobile alternators are rebuilt, and glass and cardboard are collected and recycled.

An innovative experiment that is a commercial success, this enterprise provides on-the-job training that will eventually permit many of its employees to leave and find work elsewhere. In addition, an after-hours Life Skills Program teaches skills such as taking a bus, banking, cooking a meal, or balancing a budget.

Suggested audience: board members, sheltered workshop staff, private businessmen, employment training and development agencies, vocational conselors, parents, rehabilitation agencies and counselors, educators, social workers.

Recommended use: employment training, counseling, sensitivity training, consumer workshops.

TRANSITIONS

29 minutes

Perennial Education, Inc.

This film features three disabled adults (with Cerebral Palsy and Down's syndrome) who challenge society and themselves in their search for freedom and equality. Two of the adults lived in institutions most of their lives. They each tell the story of their fight for the opportunity to work, to live independently, and to be given a chance to prove themselves.

Suggested audience: consumers, parents, service groups, civic groups, church groups, P.T.A., inservice training, board members, neighborhood groups, educators.

Recommended use: advocacy, board and care operator training, parent workshops, speakers bureau, sensitivity training, orientations.

TRY ANOTHER WAY

27 minutes

Film Productions/Indianapolis

The first in a series of films on the teaching technology developed by Marc Gold. It demonstrates the "Try Another Way" approach of teaching complex assembly tasks to mentally retarded and autistic people functioning at all levels, using a nonverbal approach.

Suggested audience: parents, vocational counselors; teachers, social workers, employers

Recommended use: advocacy, board and care operator training, parent workshops, speakers bureau, sensitivity training, orientations.

WHAT WAS I SUPPOSED TO DO? 28 minutes

James Stanfield Film Associates

Via first-hand accounts of five families, the film gives insight into the impact of having a disabled child; focuses on confronting such issues as personal acceptance and understanding; discusses the problems of family interactions; and documents the typical kinds of decisions and crises that parents of special children often encounter.

The film brings hope to families who may be worried and confused about their future and to those who will help them find solutions to their problems.

Suggested audience: parents, professionals, medical society, nursing organizations and college students in early childhood education and social work.

Recommended use: workshops, parent organizations, in-service hospital orientation, and college classroom use. (Suggested as a companion film to "Matter of Expectations and Early Intervention")

THE YELLOW SCHOONER TO BYZANTIUM time unstated

National Association for Retarded Citizens

Discusses the right to education for the severely disabled.

NAMES AND ADDRESSES OF FILM DISTRIBUTORS

Alfred Higgins Productions, Inc.
9100 Sunset Boulevard
Los Angeles, CA 90069

California Association for
Neurologically Handicapped Children
Emily Mannion
237 Los Altos Drive
Kensington, CA 94708

Colorado Epilipsy Association
1835 Gaylord Street
Denver, Colorado 80206

CRM/McGraw Films
110 15th Street
Delmar, CA 92014

Distribution Specialist
Office of Instructional Television
University of California - Davis
Davis, CA 95616

Epilepsy Foundation of America
Materials Cener
1828 L Street, N.W., Suite 406
Washington, DC

Epilepsy Society of Mass.
20 Providence STreet
Boston, MA 02116

Film Makers Libraries
133 East 58th Street, Suite 703A
New York, NY 10022

Hallmark Films and Recordings Inc.
Education Department
51-53 New Plant Court
Owings Mills, Maryland 21117

Indiana University Film Library
Audio Visual Center
Bloomingtonl, Indiana 47401

Lawren Productions, Inc.
P.O. Box 666
Mendocino, CA 95460

Malibu Films
Box 428
Malibu, CA 90265

Physicians for Automotive Safety
P.O. Box 208
Rye, New York 10580

Pyramid
Boc 1048
Santa Monica, CA 90406

Society for Nutrition Education
2140 Shattuck Avenue
Berkeley, Ca 94704

South Bay Mayor's Committee
2409 North Sepulveda Blvd., Suite 202
Manhattan Beach, CA 90266

SFA, James Stanfield Film Associates
P.O. Box 1983
Santa Mocica CA 90406

Film Productinos/Indianapolis
128 East 36th Street
Indianapolis, Indiana 46205

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GLOSSARY

Ecological or environmental inventory: a process by which parents and/or caregivers, and teachers evaluate a student's functioning level in activities (e.g., dressing) within current and future environments (e.g., home) and subenvironments (e.g., bedroom). The person evaluating the student pays attention to the behaviors required by a nondisabled person in these environments, and assesses which of these behaviors the student has, whether adaptations will be required, and how critical this behavior or skill is to the student's functioning.

Facilitator: The definition of "to facilitate" is "to expedite, simplify or ease". A facilitator of a parent support group such as the one described in the PACT is a parent or professional who helps parents clarify their goals, set objectives, acquire information or training and take action on specific topics or issues. The facilitator employs nondirective techniques in an effort to move parents toward self-advocacy and self-direction.

Integration: Ongoing, structured interactions between severely disabled and nondisabled (regular education) students who attend regular public school together. The students with severe disabilities have their own self-contained class on the regular school campus and participate with nondisabled pupils for (primarily) nonacademic periods/activities (i.e., lunch, recess, gym, music, art, halway passing, assemblies, field trips, clubs, peer tutoring and special friends programs). Please see the Project REACH Administrator's Manual (PRAM) and the Awareness and Inservice Manual (AIM) for further information.

Normalization: the use of culturally normative means to offer a person life conditions at least as good as the average citizen's and to enhance or support personal behavior, appearance, experience, status, and reputation to the greatest degree possible, according to the given individual's needs. (Wolfensberger, W., 196[illegible])

Operant training: "Operant" is defined as "operating to produce effects". In the instruction of students with severe disabilities, this term refers to the use of systematic behavior management techniques (e.g., setting specific individualized objectives, breaking these down into components, and finding appropriate reinforcers or rewards) to insure a student's acquisition of new skills.

Outreach: This term refers to groups and service providers connecting with others who have similar goals to "network", or make sure that the appropriate groups in the community are aware of their existence and purpose.

Partial Participation: A physically disabled student may not be able to "fully" participate in an activity: for example, her fine motor difficulties may prevent her from turning on a washing machine, and her restriction to a wheelchair may prevent her from putting clothes in a top-loading washer because of its height. However, the same student may be able to load and unload a dryer, given a basket placed in front of her and the dryer. This is simply one example of partially participating in a functional activity. Partial participation is equally as valuable and critical for this student's growth as is full participation for a less disabled individual.

Practicum: A term used to denote a university-supervised voluntary position as a teacher-in-training of severely disabled students. Practica usually occur in conjunction with coursework when the student is on a graduate level, prior to his or her student teaching experience.

Regional Center: The State of California contracts annually with a network of privately operated nonprofit regional centers to provide information, diagnosis referral, and ongoing case management on a "fee for service" basis, to all individuals who are diagnosed as having developmental disabilities (e.g., cerebral palsy, mental retardation, epilepsy). The regional center provides the funding to specific vendors (e.g., adult vocational programs, respite care providers) for their services to individuals.

Task Analysis: The breakdown of a student's learning objective for a specific skill into smaller components. Task analyses (or TA's) are individualized according to the particular adaptations required for that student to complete the task. The "TA" will also include information about all the procedures to be employed by the teacher who is working with the student.