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#### ABSTRACT .

Supplementing a national survey of self-help group members, a study examined the functioning of an epilepsy self-help group in order to identify communication patterns establishing mutual aid. An examination of eight tape-recorded sessions was combined with an observer's field notes to develop a profile of the group. Analysis revealed a loosely structured, "drop-in" group that was sustained by a core of from five to eight leaders. The group met with no success in engaging in collective action or advocacy and with mixed success in providing guidance for members in their daily lives. Continuance of the group seemed to be a result of its success in establishing a network of social relationships for members. The findings support the results of the national survey, which indicated that epilepsy self-help groups function as social support systems for their members. (Extensive excerpts of the recorded sessions are appended.) (Author/FL)



Talk as social support: Communication in an epilepsy self-help group

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### International Communication Association

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TALK AS SOCIAL SUPPORT: COMMUNICATION IN AN EPILEPSY SELF-HELP GROUP

#### Abstract

This study is an intensive examination of the functioning of an epilepsy self-help group. Supplementing a national survey of self-help group members, the study sought to identify patterns of communication through which members aid one another. Analysis of eight tape-recorded sessions was combined with an observer's field notes to develop a profile of the group. Analysis revealed a loosely-structured, "drop-in" group which was sustained by a core of 5 to 8 leaders. This group met with no success in engaging in collective action or advocacy and with mixed success in providing guidance for members to use in their daily lives. Continuance of this voluntary group seems to be a result of its success in establishing a network of social relationships for members. These findings further support the results of the national survey, which indicate that epilepsy self-help groups function as social support systems for their members.

The recent proliferation of medical self-help groups has attracted the attention of researchers interested in studying the role of small groups in inducing individual change. Hartman (1979) suggested that an examination of self-help groups could provide a broader perspective on the change process. In particular, study of these "pragmatically oriented" groups can overcome the conceptual limitations of research on the effectiveness of group psychotherapy. As Lieberman (1974) noted:

Theories of personal change in groups generally give great emphasis to concepts addressed to the relationship of the leader to the collectivity of people to be changed (patients, members, participants). Similar to theories of individual therapy, they emphasize the central importance of the leader or therapist.

Self-help groups provide an opportunity to examine aspects of interpersonal influence in groups which are not controlled by a professionally-trained leader, therapist, or facilitator.

The present study is part of a series of research projects focusing on self-help groups for people with epilepsy (Arntson, 1980; Droge, 1980; Norton, 1980; Droge, Arntson, & Norton, 1981). The major proposition underlying this series of investigations is that epilepsy self-help groups function as planned social support systems. Although the full rationale for this proposition has been outlined previously (Droge et. al., 1981), it will be summarized briefly here.

Epilepsy is both a medical condition and a social label. To be "epileptic" is to encounter social prejudice. This prejudice stems from the stigma surrounding epilepsy. This stigma, which is focused on seizure occurrence, results in the social isolation of many people with epilepsy. Social prejudice, rather than the medical condition itself, is considered a major cause of the



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psychological and social problems many people with epilepsy experience.

Despite the social origins of these problems, rehabilitation efforts directed at people with epilepsy are usually psychological in character. Anchored in a symbolic interactionist perspective, these standard rehabilitation efforts link social stigma with a "damaged" self-concept. By presupposing a causal relationship between stigma and self-concept, professionals engaged in rehabilitation of people with epilepsy direct their efforts at the individual victimized by the social label, rather than the prejudice of non-epileptics.

Provision of social support systems represents an alternative to the "psychologizing" of these problems. Support systems are not remedial in character. By providing an individual with a refuge from social prejudice and an opportunity to share information with others who share similar consequences of social stigma, self-help groups can augment the individual's ability to cope with prejudice. The Droge et. al. study, which examined the responses of self-help group members to a national survey, revealed that both the opportunity for group members to become "experts" by sharing experiences and the opportunity to meet informally with one another outside group meetings (e.g. at post-meeting "restaurant sessions") were perceived by survey respondents as the most valuable features of self-help group participation. That study concluded that these two features highlighted the social support system functioning of epilepsy self-help groups.

The present investigation is designed to supplement the findings of the national survey with an intensive study of self-help group meetings.

Examining the content of self-help group discussions should lead to the discovery of patterns of communication through which social support systems are structured.



This investigation focuses on an epilepsy self-help group which met each Thursday evening in downtown Chicago. Several features of this group made it a suitable candidate for observation. The group had been initiated under a Self-Help Group Project administered through the Epilepsy Foundation of America with a grant from the Department of Health, Education, and Welfare. When federal funding terminated, this group was one of the few which continued to meet (Droge, 1980). The group was conducted by a volunteer leader, and many of the volunteer leaders of groups in the outlying suburbs had been members of this group at one time. Finally, the group met at the office of the local EFA chapter and was thus consistent with the criginal program's goal of developing self-help groups that were linked to local EFA chapters. Hence, although the intensive focus of this study limits the number of groups which can be examined, the group selected was pivotal in the development of self-help groups in the Chicago area.

# RESEARCH QUESTIONS

The conceptual problems underlying research on individual change in the small group settings render conventional theories of individual change and concommitant formal research methods of limited value for the present study. Hence a decision was made to adopt an ethnographic research strategy. As Hymes (1974) notes, this strategy leads to an investigation of

communication from the standpoint of the community itself, and to see its members as sources of shared knowledge and insight.

The present study was designed to allow self-help group structure and functions to emerge from the content of discussions in group sessions and to minimize the imposition of a priori hypotheses or theoretical perspectives on the collection of data.



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The ethnographic character of this study led to the development of a set of broad research questions. This set of questions was formulated in collaboration with self-help group leaders who were members of the Epilepsy Self-Help Group Workshop (for a comprehensive description of this Workshop see Borman, Davies, & Droge, 1979). The questions focused on the following areas:

### Participation

This group had no formal requirements for membership, no specified "agenda" for each session, and no articulated means of terminating membership. The first set of questions concerns patterns of group participation.

What is the size of the group? How frequently do members attend? Under what circumstances do members enter the group? Under what circumstances do they leave?

# Group structure

A central problem for any group is maintenance of order. In this group the absence of a specified agenda may make the maintenance of order more difficult. Problems of overly talkative or reticent members, which emerge in many groups, may be especially troubling for individuals experiencing the social isolation which can accompany epilepsy. Floor management and leadership issues must be resolved, or the group will degenerate into chaos.

What ground rules exist for group sessions? How is order maintained? What is the leadership structure of the group?

#### Content

A central feature of self-help groups is the offering of advice and sharing of experiences by fellow-sufferers. The discussion topics are a



rough index of the issues surrounding epilepsy which are considered most important by group members. The advice and experiences recounted define the nature of "self-help" more clearly than any other feature of group sessions.

What topics are discussed in this group? What topics are discussed most often? Which are discussed rarely? What kind of help (advice, suggestions, sharing experiences, etc.) is offered.

#### Outcome

In order to sustain its existence, the group needs either to retain current members, or attract new members, or both. The means to this end center around members' conceptions of aspects of the group which are most helpful. Since this study focus on these conceptions as part of the group's definition of itself, external outcome criteria are not considered.

What aspects of the group are seen by members as helpful? What aspects are perceived as potentially harmful? What steps, if any, are taken to prevent harm?

#### **PROCEDURES**

Late in 1978, several group members were approached at an Epilepsy Self-Help Group Workshop meeting and asked if an observer could begin attending group meetings. They replied that the decision to allow an observer to attend must be made by the group itself and invited the observer to come to the next meeting to let the group decide. At that meeting one of the group's leaders introduced the observer, described the Workshop, and asked for a vote. After the group voted its approval, attendance at group sessions and other events (e.g., social events at one member's home) continued for approximately eight months.



### Data collection

Data collection began with the preparation of written summaries of each weekly session. These summaries were based on notes taken by the observer. After attending the first two sessions, however, the observer obtained permission to record group sessions on audiotape, subject to restrictions established by group members. Eight consecutive sessions, which occurred during the first three months of 1979, were recorded.

### Analysis

Data analysis in this study is directed toward a representation of the content of group sessions. A preliminary review of written summaries and tape recordings led to the identification of two broad categories of discussion topics: personal issues raised by individual members, and topics relating to the group itself, including calls for or reports of collective action.

A second review of recordings led to the extraction of all topics introduced in the eight sessions. These individual topics were organized into categories under these two broad headings to obtain a rough profile of the character of discussions in this group. Because these topics also were indexed by date and group member, a profile of each member's participation and of the character of discussions in each session could be drawn.

Although the topic summary could provide a means of characterizing the discussions in this group, this summary was inadequate in describing the kind of aid offered by members to one another. In order to define the kind of aid offered more clearly, three excerpts from the recorded sessions were transcribed. These excerpts are contained in the Appendix of this report. The first excerpt is a description of the group's "ground rules" by one of the leaders. The other two excerpts are included because group members indicated that each segment was tied to a dramatic event which occurred



shortly after the episode reported. From the viewpoint of group members, these two excerpts seem to represent both the "most helpful" and "least helpful" aspects of the group.

Several features of a notational system developed by Gail Jefferson Schenkein (1978) have been utilized in preparing these transcripts. In this notational scheme a bracket indicates simultaneous or overlapping speech, an equals sign indicates contiguous speech (two utterances with no pause between them), and parentheses indicate that the utterance is unintelligible or that doubt exists as to the accuracy of the words transcribed. To protect the confidentiality of group members, individuals are represented in codified form. This code includes the initial of the first name of the individual followed by a number which differentiates between members with identical first initials. Finally, these formal representations were augmented with narrative detail from field notes to provide a more comprehensive portrait of the group.

#### RESULTS

# <u>Intrusiveness</u>

Before detailing the results of this study, two issues need to be addressed. The first issue is the potential problem of distortion of group activity in the presence of an outside observer and tape recorder. A description of the ways in which group members handled the presence of the observer and recorder is important in assessing the degree of distortion introduced by the presence of the observer in group sessions.

The manner in which the observer's presence was managed is indicative of the decision-making procedures employed by this group. The presence of the observer and, later, the allowance of tape recordings were approved by voice vote. In a subsequent meeting three of the group's leaders suggested



that an employment counselor from the Chicago EFA office be invited to meet with the group. Again, the decision was affirmed by majority vote of the entire group. During the course of the observer's attendance at group sessions, votes were taken only on a decision to allow "outsiders" to attend group sessions.

Second, the group established a series of "ground rules" to cover the presence of the observer and tape recorder. The most comprehensive description of these rules, which were developed by the group without consulting the observer, is contained in the first excerpt in the Appendix. In lines 1.126 to 1.156, member S1 describes the observer's involvement in the group, the purpose of the research project as S1 perceives it, and these ground rules. Any group member could request either that the recorder be turned off, or that the observer leave the room, or both. The presence of at least one new member at each session meant that the ground rules were repeated almost every week. Although the observer was never asked to leave the session, on two occasions a group member requested that the recorder be turned off. On both occasions the request was honored. Presence of the observer and recorder were thus initiated by a vote of the entire group and continued only with the consent of all group members.

### Local history

A second area of limitations to these results centers on the events surrounding these group sessions. This group had been initiated by a "Peer Counselor," an individual who had been employed during the EFA project and who had continued as a staff member of the local chapter after that project terminated. Prior to the first recorded session a group member announced the impending resignation of the current Peer Counselor. In that session, and for several weeks following this announcement, group members were urged to



apply for this position. No fewer than six members expressed a desire at one time or another to fill this position. Two years later, a group member remarked that this time had been "a little crazy," with members competing for the job and not knowing who might be selected to fill it. Hence it is likely that some members were acting as "counselors" to impress chapter staff with their qualifications as Feer Counselors. The discussions may reflect this competition to be "helpful" to demonstrate competence as a Feer Counselor as much as patterns of peer support. Sadly, the vacancy was never filled.

Despite this lack of continuity, the group continued to meet weekly at the chapter office.

This changed circumstance overlapped with another evolving situation.

The original Peer Counselor had developed an "advocacy group" which met on Monday afternoons. This group was formed to engage in consumer advocacy through public education regarding epilepsy and to provide volunteers for chapter activities such as participation in health fairs, advertising campaigns, and fund-raising for the local EFA chapter. This group, which consisted of people who were also members of the self-help group, began experiencing difficulties which entered into the self-help group discussions.

Three specific problems of the advocacy group became part of the agenda of the self-help group. First, several advocacy group members expressed concern of the poor participation and inactivity of this group. In the third recorded session one group member announced that a portion of the self-help group session would be set aside for advocacy group business. Unlike the decision to allow "outsiders" to attend sessions, no vote was taken. Second, the absence of a Peer Counselor led to an increasingly confused situation regarding the relationship between group members and local chapter staff. In one instance a senior staff member attended a meeting and informed members that the office routine of the chapter was disrupted



by group members who were "hanging around" the office. On a number of occasions one group member, who was also employed by the chapter as a receptionist, vetoed several members' suggestions for fund-raising activity, claiming special information because of her employment situation. The third difficulty with advocacy activities was a recent change in the Illinois Mental Health code which stipulated that no "client" of a social service agency could volunteer for a task which was part of the job description of a paid staff member, unless the task was part of a treatment contract. Although this new Code was designed to prevent agencies from extracting free labor from clients, this new legislation also reduced opportunities for self-help group members to volunteer for fund-raising or public education efforts. The distance between group members and local chapter staff was increased significantly by this changed legislation.

The possibility that observer intrusiveness distorted group events, although present, seems remote in this instance because the group maintained control of the presence of both observer and recorder. Events peculiar to this group at the time of the study, however, may have distorted these results.

### Participation

This group met each Thursday evening from six-thirty until approximately nine o'clock. Many members went to a nearby restaurant after the meeting. These post-meeting gatherings could last until midnight. In addition, at the time of this study several members met before each session at a nearby fast-food restaurant. Several group members, then, spent at least six hours each Thursday in the company of other people with epilepsy. This analysis focuses on the characteristics of that involvement.

Over the course of the eight recorded sessions 33 people attended at least one meeting. Between nine and 19 members were present at each session.



An average of slightly more than 14 people attended each session. Each individual attended, on the average, 3.3 of the eight meetings. During these sessions, only one person attended one meeting and failed to return. Others who attended one or two sessions either were returning members who had been absent for a time or continued to attend after the recorded sessions were over.

Although the group met for two-and-one-half hours, some members arrived later and others would leave before the nine o'clock ending time. In addition, telephone calls from absent members occurred during each session. On one occasion an absent member asked to listen in over the telephone, and one group member relayed the unfolding session to this absent member over the telephone.

No formal procedures for entry into or exit from the group existed.

During the course of the eight recorded sessions, three members announced, either in person or by relaying a message through one of the group leaders, that a new job led to time conflicts which prevented their attending the group. No other public announcement of a member's leaving was made. The "drop-in" character of this group created a situation in which no expectations for regular attendance were made explicit. Most members who had been absent, however, were queried by a group leader about events which had occurred in their personal lives during their absence.

chapter appeared to be the most frequently-used source of new group members.

New members were usually asked to describe their seizure history and patterns,
living situation, and employment status. In addition, a group leader would

explain the ground rules at least once during each session. New members were
seldom asked why they had come to a meeting. Instead, they were directed to
observe the group session to see how it worked.



# Structure

In the absence of written rules and guidelines, ground rules and group structure were described to new members during their first group session.

These statements represent the group leaders' perceptions of how the group worked. During one session member Si provided an elaborated statement of these rules. Although it is summarized here, the description is contained in the appendix. In the first section (1.1 to 1.25) four aspects of these ground rules are described. First, Si introduces the purpose of the group—

"we. . . listen to each other's problems and come up with an idea——corrects himself by stressing the individual's responsibility for taking action—

"or a bunch of ideas that a person can play with and come up with their

own idea——mentions the central feature of group membership——"an ear that... .

can understand what the hell the problem is. . . this is a private little club. . . you gotta have epilepsy before you can be a member——and, finally, emphasizes in detail the importance of confidentiality.

Next S1 describes the purpose of the observer and tape recorder, and emphasizes the right of any individual to ask that the discussion remain private among group members. In the final section (1.74 to 1.84), S1 mentions the fact that members are not always sympathetic and urges new members not to abandon the group--"If it upsets you guys. . . don't hold it against everybody. Come back again."

Although the overt description of group sessions by a leader is an indicator of group structure, it may present an overly coherent picture of the group's operation by leaving out the prospects for disorder. In this self-help group maintenance of order was a problem. The giving of a "bunch of ideas" often led to a situation in which several members would talk at once, resulting in the group leader's shouting for order. An example of this problem occurs in Excerpt Two in the Appendix. At 2.88 several members suggest that Il "take a GED," an adult education program that leads to a high school diploma.



At that point (2.95) Pl and Sl, two of the group's leaders, attempt to restore order. Although Sl succeeds in holding the floor, Pl continues to insist that he had ignored her attempts to restore order—"I was taking it, /Sl/...Listen, I was just about to say the same damn thing." Once order was restored, Il revealed that he had completed his high school education in a Job Corps program.

This incident exemplifies the frequently chaotic nature of the group sessions. Although the overall procedure was a "round robin" in which each member had a "turn" to discuss a problem or issue, the discussion was seldom calm and orderly. Members would suddenly leave the meeting room for coffee, a cigarette, or a private conference in another part of the office complex; others would leave to go to a restroom on another floor of the building; some would engage in telephone conversations while in the meeting room; and some members would enter late and immediately take over the floor, interrupting any discussion in progress. Hence the characterization of group sessions provided in S1's descriptions tends to make the discussion seem more orderly than it was.

This confusion surrounding the maintenance of order highlights a more general ambituity in identifying the leadership structure of this group.

Because the Chicago group emphasized the non-professional nature of self-help, no guidelines for leaders were developed, nor did a leadership training program exist. In the absence of formal procedures for conducting sessions, however, responsibility for guiding discussions fell on the shoulders of some members more than others. Because the behavior of these group leaders, rather than formal rules of procedure, directed group sessions, examination of the behavior of these leaders was undertaken.

Direct observation of this group led to the perception that this subgroup of "leaders" attended meetings more frequently, were more likely to change



the discussion topic, and appeared to direct the discussion more toward the process of the group, rather than raise personal issues. A more formal examination of these aspects of leader behavior was undertaken using the topic summaries extracted from the recordings of group sessions.

Behavioral correlates of leadership structure in this group may be assessed from the information included in Table One. In this Table each group member is indicated by the appropriate code. Members are listed in order of frequency of attendance.

A first criterion for assessing leadership structure is frequency of attendance. The mean number of sessions attended (3.3) is utilized as a decision rule. Only those members who attended four or more sessions were considered as potential leaders. This first criterion left 13 of the 33 members eligible. A second criterion is number of topics introduced per session. Given the "round robin" procedure of this group, each member can be expected to have at least one "turn" in each session. A higher number of turns per session is an indicator of control of the agenda of discussion in the group. Average number of topics per session was 2.14. Only six of the 13 members who attended at least four sessions had more than this average number. Finally, leaders were thought to be those individuals whose comments were directed toward the process of the group itself. Given that two-thirds of the topics introduced in each session were personal issues, this criterion may be the most effective behavioral indicator of group leadership. The average of group-related topics was 274 per member.

If all three criteria are used, five members emerge as leaders of this group. All five also were members of the Epilepsy Self-Help Group Workshop. Since participants in the Workshop were considered "group leaders," Workshop membership serves as an external criterion for leadership. In this case these behavioral criteria seem to differentiate leaders from other self-help group participants. One other Workshop member met two of these criteria,



TABLE ONE
MEMBER PARTICIPATION

Individual	Number of Sessions	Individual Topics	Group Topics	Total Topics	Topics/ Session	Group Topic Percentage
El	8	ë	12	14	1 35	47
G1	8	2 17		<u>25</u>	1.75 3.125	75 20
P1	8	īž	ğ	<u>2</u> 2	2.50	32
G2	7	14	6	20	2.85	60
S1	<u>6</u>	6	8 8 6 15	<u>20</u> 21	3.50	30
H1	6	11	1.	12	2.00	72 72
R1	5	12	1. 5.0 2.2 2.2 2.2 2.0 0.0 2.0	17	3.40	08 29
S2	5	9	2		1.80	
D1	4	Ź	2	9: 9: 8: 5: 7: 5: 3: 3: 4:2	2.25	00
<u>F</u> 1	4	6	2	2	2.23	22 25
<b>B</b> 1	4		2	<u>o</u> 5	<u>2</u> .00 <u>1</u> . <u>25</u>	2 <del>5</del>
11	4	3 5 3 3 3 2 2	5	<u> </u>	1.75	40 29
L1	4	Š	5	<u> </u>	1.25	40 40
K1	4 3 3 3 3 3 2 2 2 2 2 2	Š	ē	2 3	1.22	90 00
P1	3	Š	ŏ	ي. ح	1.00	<b>9</b> 0
Ml	3	. 2	ž		1.25_	
B2	· <u>3</u>	2	ก็	7 2	667	50
J1	3				3.67	00
F2	3	9 2	2 0 5 2 0	11 2 6 4 3 5 3	.667	18
J2	<u></u>	ī	Š	<u>,</u>	2.00	00
P2	2	2	j j	<del>,</del>	2.00	83 50
K2		3	â		1.50	50
<b>B2</b>	2	5	Ö	ے ج	2.50	00
M2	$ar{2}$	3	ŏ	بر ع	1.50	<u>0</u> 0
G3	<b>2</b>	ĭ	ŏ	ر آ	.50	00
м3	ī	2	ŏ	÷	2.00	00
L2	Ī	2	ĭ	2 3	3.00	<u>00</u>
E2	ī	3	i	<b>4</b>	3.00 4.00	33
D2	i	4	ō	<b>4</b>	4:00	<u>25</u>
ĀΊ	ī	Ō	ĺ	i	1.00	00 100
<del>j</del> j	ī	3	ī	4	4.00	
Ã2	i	<u> </u>	ō	4	4.00	2 <u>5</u> 00
R2	1 1	i	ŏ	1	1.00	00

Source: recordings of eight meetings downtown Chicago epilepsy self-help group



and two other Workshop participants met one criterion. Only one individual identified by these criteria was not included in the Workshop. That individual's participation may be distorted by the fact that he asked to be "moderator" of one session. During the sixth recorded session this member (R1) telephoned to report he had obtained a job which prevented him from attending the Thursday night sessions.

Continuity of structure in this group was achieved by a "core" of five to eight group leaders. In general, these leaders attended meetings more frequently and were more likely to initiate new discussion topics than were other members. More importantly, members of this leadership core were more likely to turn the conversation to the functioning of the group itself.

## Content

Over the course of the eight recorded sessions, 249 different topics were introduced. An average of 31 topics were introduced in each session.

167 (67%) of these topics were personal issues. The range of issues raised was:

Employment—The greatest number of personal issues focussed on employment.

One quarter of all personal issues introduced concerned some aspect of employment. Of the 42 times employment was raised as an issue, reports of loss or denial of a job occurred 10 times. Four reports of harassment by employers were introduced. Reports of gaining employment or returning to a job occurred six times, and a report of support from an employer occurred once. In addition, reports of job-seeking activity or the desire for employment occurred ten times. General advice on employment, including how and when to let an employer know about epilepsy, the importance of persistence, and advice on how to get back into the job market after a long absence occurred ten times. Finally, a description of one's present job duties occurred once.

Seizures--The second most frequently occurring subject for this group
was seizure history and activity. This topic accounted for 16
per cent of all personal issues raised. Reports of weekly seizure
activity or specific episodes occurred sixteen times, and a general
history and description of seizure activity was reported ten
times, usually by new members. Those members (e.g., H1, S2)
who attended the group frequently but were not group leaders
would begin their "turn" by reporting the week's seizure activities.
Frequently they would stop after this description, leading one
of the group's leaders to "prod" them about seeking employment.



- Social Service Programs--14 per cent of the personal issues raised focussed on available social service programs. Obtaining financial assistance through Supplemental Social Security Insurance (SSI) or the Illinois Department of Vocational Rehabilitation (DVR) occurred nine times. Participation in employment development programs such as DVR or the Jewish Vocational Service (JVS) was raised six times, and discussion of working with the EFA employment counselor occurred six times.
- Family Relationships—11% of these topics concerned relationships with family members. Problems with parents were discussed five times. Losing custody of a child because of having epilepsy was raised five times, all by the same member. Similarly, one member raised a concern over revealing epilepsy to family members five times. Another member reported twice that he had turned his brothers in to the police for smoking marijuana, and one member indicated that his parents had been supportive.
- Change in the amount or kind of anticonvulsant medical care.

  Change in the amount or kind of anticonvulsant medication was reported three times, and the importance of keeping a record of seizure activity for one's physician also was introduced three times. One member reported twice that he was about to see a hypnotist for treatment of his epilepsy, and positive feelings about a particular doctor, a report in change in diagnosis of seizure type, a general discussion about leukemia, and a discussion of a medical problem other than epilepsy all were raised once.
- Discussion of current schooling occurred five times, contemplation of a return to school for vocational training occurred twice, and problems finishing high school due to harassment from other students or memory problems were mentioned twice.
- Transportation--5% of the personal issues raised concerned transportation.

  Difficulty obtaining a driver's license or an automobile was introduced three times. The possibility of obtaining a reduced-fare pass on the public transportation system was discussed twice. One member reported on his travels during the week twice, and a member raised the problem of transportation for blind persons once.
- Police/paramedic problems--5% of the issues raised concerned problems with police or paramedics. One member reported twice on an incident in which she was arrested while carrying unlabelled anticonvulsant medications and no identification which indicated she experienced epilepsy. One member reported on a past incident of police harassment, and one member told of escaping a paramedic unit after a seizure. This last discussion revealed a concern expressed by several members. Well-meaning bystanders frequently will call an emergency medical unit when they see a seizure. This action can result in a costly ride to a hospital if the person with epilepsy cannot convince the paramedics that he or she has experienced a seizure. Hence this individual reported he "got away" from the paramedics to avoid paying for a trip to a hospital.



- Residence--5% of the personal issues raised concerned members' residences.

  Two members reported to the group on their attempts to move out of a Supported Living Apartment (a program designed to give handicapped persons experience in managing a household before they attempt living independently) and obtain a private apartment a total of six times, and one member announced the impending conversion of his apartment building to a condominium.
- Description of week's activities—5% of the individual issues raised were reports of a member's activities during the week. These reports raised no problems or issues.
- Other topics--7% of the individual issues raised were in other categories. Romantic relationships were discussed three times,
  three members reported being denied entrance to or ejected from
  military service because of epilepsy, a discussion of an upcoming
  mayoral election occurred once, and a report on a television news
  segment concerning epilepsy occurred once.

Topics related to the structure and activities of the group occurred 82 times, accounding for 33% of all topics raised. The range of group-specific topics was:

- Group structure and member behavior -- 28% of group-related topics fell in this category. Topics aimed at correcting the behavior of individual members, including proper behavior at the restaurant, keeping calm during discussions, and a lecture after someone had violated a ground rule regarding confidentiality, occurred six times, Description of the group to new member and announcements concerning the appearance of the Peer Counselor on a local television program occurred eight times. A call for order occurred five times, and a call for a vote to allow the Employment Counselor to visit the group occurred four times.
- Advocacy-21% of group-related topics concerned collective action or advocacy. Seven of these topics were reports of the activities of the advocacy group. Reports of and calls for advertising campaigns occurred seven times. Calls for political action (e.g., writing letters to legislators or signing petitions) occurred four times, and one member told a story of the participation of three group members at a past Health Fair.
- Peer Counselor Replacement--12% of group-related topics focussed on the Peer Counselor vacancy. This topic arose 10 times. Eventually, one of the group leaders suggested that every self-help group member apply for the position.
- Problems with Local Chapter--10% of the topics relating to the group concerned difficulties with the local chapter. On four different occasions a theft occurred in the office between the close of business Thursday and the next Friday morning. Members of the group were suspected of these thefts, and group leaders were asked to relinquish their office keys. The change in the mental health code prohibiting many volunteer activities of group members was discussed twice. The request by chapter staff that group members



stay away from the office during the day was raised once, as was one member's report of difficulties getting a telephone message to the Peer Counselor.

- Testimony--Members' detailing of how the group had helped them occurred seven times, accounting for 8% of group-related topics.
- Other Groups--Six times, or 7% of total group-related topics, members recounted difficulties in starting other epilepsy self-help groups.
- members of the group (usually roommates in the SLA).
- Workshop Information--the Epilepsy Self-Help Group Workshop was introduced five times over the course of these eight sessions.

### Outcome

Results related to group outcomes focus on two episodes which occurred during the recorded sessions and which were identified by group members as affecting subsequent events for a participant. A full transcript of each episode is included in the Appendix. Excerpt Two begins with a poem read by a member (II). This member was depressed because he had lost a job recently. One week later II reported that he had found another job. In that later meeting he specifically identified this session as leading to his obtaining a job. Excerpt Three occurred on February 22, 1979. The day after this episode, member P2 experienced multiple seizures and telephoned two group leaders, who eventually took her to a hospital. At the next group meeting these group leaders identified this episode as precipitating P2's seizures, although they expressed a suspicion that the seizure episodes might have been feigned. Hence the excerpted statements identify instances in which the group's efforts were perceived as particularly helpful or harmful by members themselves. These two excerpts are summarized below.

### Excerpt Two

This episode begins when Si turns the floor over to Il. Prior to this episode, Ri had been the focus of group attention, describing his job-seeking activities during the previous week. Il reads "something...



3

I just wrote up," a short poem which ends with the line, "I'm the young man whose life soon will end." No one responds. As he begins to elaborate on his poem, other members start to respond (2.17). Li aliudes to an earlier discussion "downstairs (in the fast food restaurant)" and sets the tone for the advice offered next--"Practice what you preach." In turn G2, S1, and F2 encourage I1 to persist in job-seeking. I1 expands on his previous statement, expressing a belief that no one gives people "that's in our state of mind" a chance. S1 attempts to focus the attention of I1 on the actions of the group (2.43). J1 begins by agreeing with S1, then changes the focus of conversation from I1's feeling to the fact that an interviewer may be "down in the dumps" and tells I1 that he shouldn't "put all the blame on yourself." Il repeats his feeling of depression (2.70) L1 and F2 repeat the "Practice what you preach" advice.

Jl persists with her explanation that anyone may be turned down for a job if the employer "feels lousy" (2.78). Il offers another reason for his depression -- "They wouldn't even let me finish high school." At this point four group members attempt to offer advice about the GED program, and two leaders move to restore order (2.95); However, these two group leaders begin to argue over whether S1's lengthy "lecture" was necessary at that time. G2 tries to speak to both leaders but is cull off. Il re-takes the floor (2:125) and elaborates on his: situation. When G2 attempts to interrupt (2.132), this interruption is vetoed by J1, and I1 continues. Il's elaboration begins with a reference to the local chapter staff member's visit which had occurred earlier that evening--"what the man was saying when he was here"-and proceeds to the recounting of some advice from his mother to "take a desk job"--advice he rejected. Il next explains his pain over not being allowed to "build things (which he excels at)," because of "some thing down on. . . this application" finally reached "the boiling point." Although he began this excerpt expressing depression, he ends this explanation:"I'll break his neck," referring to some unnamed employer. He then announces he is finished (2.154)

Next G2 provides inspirational advice—"the best thing in the world you can build is /II/, which is you"—compares Il's situation to his own, and concludes by advising Il to "keep a positive attitude." Jl next tries to clarify the GED issue (2.174), but instead precipitates a disagreement with Il over whether a person with epilepsy could be prevented from completing high school in Chicago. Next Jl suggests that some jobs may be too dangerous for people with epilepsy. Il responds that he has been careful and has followed previous advice from his father about "not being suited for high places." Il continues to disagree and elaborates on his own background at 2.230. Finally, G2 paraphrases Jl's statement and adds his own advice(2.256). Eventually, G2 provides an aphorism—"instead of 'I can't do,' you know what you emphasize? 'I can do.'" Jl and Sl agree, and Il echoes this advice at 2.277—"You've got to crawl before you can walk."

After an interruption II re-introduces the "practice what you preach" theme. At this point II acceeds to this advice--"Yes, ma'am." Next



F2 gets a turn to offer support by suggesting II's situation is better than his own (2.297). SI encourages II and F2 to "get together later on." G2 offers another aphorism--"if you know you're a quitter you'll never win, and if you know you're a winner you'll never quit." F2 and L1 offer encouragement. SI attempts to move the discussion on to L1 (2.315). She demurs, and he turns to P1. She shifts back to I1, and S1 asserts that the group will "kick him in the ass when need by and where need be." In the ensuing laughter II repeats the contradiction between his encouraging L1 earlier and "feeling bad about myself." S1 terminates the segment by asserting that these two group members are helping each other, and the discussion moves on to another member.

The next week II reported that he had found another job. He thanked the group in general and Si in particular for helping him during this session. He maintained that the most important thing that was said was when Sl suggested that he "go to the Salvation Army." However, this statement does not appear in the excerpted segment. Earlier in this session several members had mentioned difficulties with parents, prompting Jl to suggest that they needed to attend the Salvation Army family counseling program. Hence Il's recollection of the "help" given him during the session misattributes both the content and the source of what he considered the most important statement made.

# Excerpt Two

S1 begins by directing P2 to listen to the discussion in progress, previously, S1 and L1 had been discussing an incident in which L1 was riding on an elevated train and experienced an "aura," a physical warning of the onset of a seizure. L1 reported that she had successfully "fought off" the seizure during the aura.

The Thursday prior to this meeting P2 had experienced a seizure while riding home on the "el." Sl had accompanied her home. He directed P2 to attend to his conversation with L1. P2 replied that she had been listening and asserted that she would "try again."Sl explains that he was asking L1 about this incident for P2's benefit. P2 expands on her reasons for wanting to ride the "el" again after six years—"to expand myself as a blind individual." Sl advises P2 to keep records in order to "check herself out" before riding the "el." P2 maintains that she had taken precautions before riding that Thursday evening. She "had enough sleep" and "felt fine" after the meeting. P1 and G2 suggest that she might have been "unconsciously excited" by the meeting (3.45). P2 and Sl continue, with P2 explaining that she "felt fine" on the way to the meeting but was tired afterward, and Sl suggesting that her being tired and the "extra noise" might have caused her seizure. Sl next asserts that P2 isn't understanding him and begins to restate his



advice (3.73). P2 maintains that whe was "responding," or coping with the situation. S1 reminds P2 that he had asked her to get off the train at one roint, but she had refused. P2 again maintains that she "wanted to try."

At this point (3.86) J2 interjects: "It's because you're stubborn." P2 disagrees vociferously. Although J2 tries to explain, P2 persists in holding the floor, explaining her reasons for staying on the train (3.91). She wanted to increase her independence so she would not have to "rely on anybody in general." Sl restates his advice about getting off the train for a time to prevent a seizure. J2 agrees, and S1 continues. He describes the success of his own record-keeping in enabling him to better predict seizure occurrence and finishes by stating he expected a seizure the previous Friday and "sure enough, I had three of 'em." L1 expresses surprise over S1 having three seizures in one day (3.122). El questions the advice Sl had been giving. P2, becoming upset, reasserts her determination not to quit. S1 restates the suggestions that P2 leave the "el" train if she experiences an aura. L1 supports this advice and notes that there are "so many more metal things /dangerous objects/ on the train (3.134)." P2 maintains that she knows her auras. Sl restates his suggestion that she wait for the next train if she experiences an aura.

P2 next expresses her lack of understanding of the "el" system (3.142) and asks S1: "You want to help me locate the next train?" S1 suggests that group members may be able to accompany her home from meetings. P2 points out that she needs to understand the "el" system at other times. G2 interrupts and paraphrases this statement (3.150). S1 next elaborates on his earlier advice that P2 "check herself out" before boarding the train.

J2 enters the conversation and starts explaining the train system (3.164). P2 repeats that she does not understand the system because she has not used it in six years. J2 asks P2 how she finds her way around the city. Before she can finish, P2 attempts to answer the question she though J2 was about to ask. G2 admonishes P2 to "let her ask her question." P2 waits, and replies that she asks "an individual" where she is.

At this point the recording ends. When the tape recording resumes (and a few comments have been lost), G2 is describing a situation where "there's no one on a particular train" (3.192). J2 tries to provide more information about the "el" system, using her own experience as an example. G2 responds that he is not aware of the situation she describes. J2 starts to elaborate. P2 interrupts, shouting "That's you!" four times. S1, P1, and G2 try to stop P2, with G2 urging her "not to get overemotional about this issue."

J2 and G2 next disagree over the standard procedures on the train system, each describing a personal experience (3.214 to 3.229). J2 suggests that P2 would be safer on the trains than at the platforms, especially with her guide dog--"Listen, nobody is going to do anything to you with a dog. At this point (3.231) P2 repeats the statement, "You wanna make a bet!" three times, each time louder than before. G2 disagrees with J2. S1 admonishes P2 for shouting and not listening to group members' suggestions. P2 replies that she has been listening. S1 and G2 make



calming statements at the same time. J2 starts to respond. E1 urges J2 to "get to the point." P2, still upset, recounts an incident in which she was raped even with her guide dog present. P2 continues to explain ner actions, with G2 agreeing. J2 interrupts and states, "But you have to try" (3.261). P2 shouts, "I am trying!." S1 states the group's intentions—"all we're doing is giving you a few suggestions."

P2 states she had accepted the group's suggestions. Si states that "we've misunderstood you, and you misunderstood us." P1 urges the group to "drop it" and move on. Si expands on the misunder tanding, stating that P2 seems to be "disagreeing with everything we're coming up with." E1 again disagrees with Si's advice (3.282), suggesting that instead of "fighting off a seizure," it was helpful for him to "think of something pleasant." P2 states she was trying to "think of the pleasant" during the incident on the train. J2 starts to speak. P2 interrupts and asserts, "Everyone that is sighted has their limitations, everyone!" P1 demands of P2 and J2, "Will you two cool it." At this point G2 expresses a desire to have an aura, explaining that his seizures occur without warning. The discussion abruptly shifts away from P2 to a discussion of types of auras.

Despite the multiple seizures she experienced the following day, P2 remained a group member for over a year. Eventually she married another group member, and she stopped attending group sessions only after the birth of a child. Il dropped out after he secured his new job.

#### DISCUSSION

The profile of this group which emerges from the preceding description indicates that participation in this group takes one of two forms. On the one hand, a core of between five and eight group leaders sustains the group.

Members of this leadership core attended almost every session. They were also involved in the advocacy group. They were largely responsible for controlling the disucssion topics, and, as Table One indicated, these group leaders were more likely to direct the discussion to topics related to the group's functioning. Four of these leaders introduced group-related topics much more frequently than they introduced personal issues. On the other hand, other members attended less frequently, discussed personal issues more often, and allowed the leadership core to control the group's agenda.



This leadership cadre called for a group decision on only one issue.

The presence of "outsiders"(e.g., the observer) was decided by majority vote. Other decisions were simply announced by one of the leaders. Voting on "outsider" attendance reinforced the notion that the self-help group was limited to people with epilepsy. Indeed, the observer's continuing presence was sanctioned informally by awarding him the epithet "honorary epileptic," reinforcing the group's self-definition as being exclusively for people with epilepsy.

Outside this leadership core, group participation was structured loosely.

New members were asked only about employment and seizure history. Questions regarding an individual's reasons for attending were never raised. Those attending the session merely were expected to "take a turn." They could 'simply say "my week was fine," describe their seizure activity, or raise an issue. Although other members would "offer suggestions," in most cases the responsibility for solving a problem remained with the individual member. Group membership was not contingent on any activity between sessions. Members were free to come and go, and to heed or reject the advice of other members as they chose. Appropriate circumstances for leaving the group also were ill-defined. The only public announcements of termination described situations in which the member had found a job. Other members simply drifted away.

Some returned eventually, but others disappeared altogether.

Both the dichotomy between the leadership core and peripheral members and the loose membership requirements affected the success of this group.

Three different purposes for this self-help group emerge from the sessions described in this study. This group was unsuccessful in attempts at collective action, had mixed success in guiding members' daily lives, and was most successful in providing a network of social relationships for its members.



With the demise of the Monday advocacy soup, several members of the leadership core attempted to use the self-help group to engage in collective action. This attempt proved unsuccessful for several reasons. First, the resignation of the Peer Counselor left the lines of communication and accountability between this "drop-in" group and the local EFA chapter tenuous and uncertain. Although several members were planning projects for the local chapter, their planning activities were viewed as "hanging around" by chapter staff. In addition, an unforeseen consequence of the "drop-in" character of the group exacerbated these difficulties. The occurrence of thefts from the office led to the suspicion that some people who drifted in to the meeting had drifted out with office property. Finally, the change in the state Mental Health Code had created a situation in which the "client" status of some members rendered their volunteer activities illegal.

Aside from the leadership core, members seldom expressed interest in these projects. The absence of formal membership requirements made planning for advocacy projects, which required that work be completed outside meetings, difficult to accomplish. No new projects were initiated by this group after the Monday advocacy group terminated.

Unlike the attempt to engage in collective action, which was imposed on the group by the leaders, providing advice for other members' daily lives was a manifest goal of this self-help group. This advice took the form of advice and reports of personal experiences from other members. Excerpts Two and Three are extended examples of attempts by members to help each other through conversation. Ironically, although each excerpt had a dramatically different outcome, the content of these two episodes contains many similarities. In both segments one member persists in elaborating on a piece of advice. In each episode the individual who is the target of aid is involved in an extended disagreement with another member. In both



excerpts members share relevant personal experiences. In each segment group leaders become involved in disagreements. Finally, both segments end abruptly when a group leader calls on another member. No closure on the issue being discussed was articulated.

A number of differences between these two excerpts emerges. The first difference initially appears puzzling. The nature of the "help" offered Il in the first excerpt contains general aphorisms; indeed, the only specific suggestion (taking a GED) is revealed to be inappropriate. In Excerpt Three specific suggestions regarding keeping records on seizure activity and resting when an "aura" is present are offered P2, and these suggestions are based on the experience of group members. At first glance, specific advice seems "harmful" and cliches seem "helpful."

The critical difference between these two segments does not lie in the nature of the suggestions offered, but in the tratment of the target individual by the group. In Excerpt Two II introduces the issue and completes it, announcing "I'm finished" (2.154). His emotional response changes from depression to anger, and he is able to accept the help offered. He is eventually able to articulate himself the contradiction between the advice he gave LI "downstairs" and his own feelings. Hence, despite the fact that he subsequently misattributed both the source and content of the help he received in this session, the present analysis suggests that his opportunity to control this discussion was a key to its success. This conclusion is corroborated by the findings of the survey study (Droge, et. al., 1981) in which perceived control was found to be a significant correlate of satisfaction with life in general and self-esteem.

In contrast, Excerpt Three is an example of the entrapment of the group in an attempt at helpfulness. Having been placed in the center of group



attention by S1, P2 is continually defending her actions from the advice of the group. Even when others try to come to her aid in her disagreement with Sl, the content of their helpful suggestions (e.g., that she was "unconsciously excited " or had a "stubborn" personality) imply that she was unaware of the state of her own mind. She finds herself in the position of having to prove to the group that she knows her mind as well as they do. Her blindness increasingly is inovked as part of her defense, intensifying the difference between herself and other group members. Finally, when J2 suggests whe will be safe with her guide dog, a recent trauma has been dredged up. Extremely upset, P2 recounds an indicent in which she had been raped with her dog present. In their attempts to help P2, members had dragged her into the fray, forced her to defend her actions, consistently misunderstood and interrupted her, and reminded her of a recent trauma. The issue was never successfully resolved. Like many other discussions, the topic was changed abruptly. At no time was P2 allowed to explain fully her actions. Members' attempts at helpfulness were counterproductive, triggering, at least in the minds of some group leaders, multiple seizures the next day which led to her hospitalization.

Another difference between these episodes highlights the particular focus of the mutual aid offered in this group. Excerpt Two focuses on employment, which was a major theme of this group's discussions. 25% of all personal issues raised in the group centered on employment. Finding a job appeared to be the only approved means of terminating group membership. Indeed, a member's announcement of a new job was always greeted with a burst of applause during group sessions. Employment was a major concern of this group. In contrast, Excerpt Three centers on coping with seizures. The idiosyncratic pattern of members' medical conditions rendered the specific suggestions and shared experiences of other group members of limited value in dealing with epilepsy. Hence, although seizures represented the second most frequently occurring personal issue, this frequency may have been inflated. Some members would



discuss seizure episodes during their "turn" in lieu of any other topic, and new members would introduce themselves to the group by describing seizure history. Most of the personal issues discussed (e.g., employment, social service programs, transportation, education, family relations), centered around the social consequences of the label "epileptic." Further, the advice offered in the "helpful" episode concentrated on this area, while the "harmful" advice focused on the more individualized aspects of epilepsy, the medical condition itself. The grouping of personal issues raised, along with the differences between these two excerpted episodes, is consistent with the position outlined earlier in this report that discussions which centered on coping with the stigma surrounding epilepsy were the most helpful features of the guidance group members received for their daily lives.

This group and similar ones in the Chicago area represent the only self-help group program founded during the EFA project which persisted in the form envisioned once the program terminated. Given the fact that the group met with no success in collective action land with mixed success in providing guidance for individual members, what accounts for its continuation?

Scattered throughout the present study are clues which indicate that the self-help group has become a central activity in a network of continuing social contacts among some people with epilepsy in the Chicago area. A key feature of this group is the post-meeting sessions in the restaurant. The national survey (Droge, et.al., 1981) indicated that those who attend these restaurant sessions are more likely to engage in leadership, to contact other group members outside of meetings, to be satisfied with the group, and to have limited opportunities for social contact outside the self-help group. This study also indicates that the developing relationships among group members accounts for the group's longevity. Il left after obtaining a job. P2 remained with the group, eventually marrying another



member. Two other group mambers shared an apartment for a time. Others have found romantic partners in the group. Friendships have developed.

The home of one member has become a center for summer picnics for group members as well as a place for some members to visit any time.

The social network feature of this group differentiates it from "treatment" groups, in which contact among members outside sessions is seldom encouraged and frequently prohibited. This feature also is compatible with the "social support system" perspective underlying this research effort. This group has become a source of social support for many of its members, available for their use as much or as little as they desire. When viewed from this perspective, the lack of closure on personal issues and the absence of prescribed activity between sessions means that anyone who says anything to a member raising a personal issue can consider himself or herself a part of the help offered by the group. Hence the discussions of personal issues may benefit the members offering advice as much as those receiving it (Riessman, 1965). In offering their advice members become the "experts," and those who stay in the group become repositories of this lay expertise. Following Caplan's (1972) analysis, members of the leadership core become "specialist counselors" in coping with the stigma surrounding epilepsy:

This group is sustained, then, by both kinds of participants. The peripheral members who bring in a particular problem, usually the lack of a job, and stay until that problem is resolved, are necessary to provide new targets for the help offered by regular members. In turn, the feeling that their actions are helpful to others and the network of social relations among long-term members appear to be important in sustaining their involvement in this self-help group. The findings of this intensive analysis thus corroborate the results of our survey study, indicating that epilepsy self-help groups function as social support systems for people with epilepsy.



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#### APPENDIX

# Excerpt One -- February 22, 1979

1.1 S1: Um, listen guys, you know everybody's name around here? Were you introduced to everybody? OK, all right, um, let me go over some things and, uh, what happens--what we basically get together here for is, you know, we kind of listen to each other's problems and possibly come up with an idea for that person--or a bunch of ideas that that person can play with and come up with their own idea--on how to get things going, you know, for their own good and, uh, sometimes just to hear--have--not a sympathetic ear, but

1.10

an ear that, you know, can understand what the hell the problem is, uh, and, one of the things we try and do is--once we walk out of the door, we don't talk about it, what we heard in here, unless we're talking with that person. You know, because what goes on in here is private, OK--so if you guys want to bring something up, don't worry about it, it ain't gonna go past this door unless that person who wants to ask you a question about it comes to you.

All right, they should come to you, first, before they go anywhere else. All right, 'cause, like I said, this is a private little club--gotta be--have certain specifications, in other words, you gotta have epilepsy before you can be a member, you know, and, you know, if, shall we say, something comes up we don't want the rest

1.20

of the world to know about, but we do need some advice on, you know, we want you to feel that--the group here-- if they give you advice, even if it isn't the greatest advice, they ain't gonna go and talk to anybody else, and possibly get more advice for you,

unless you ask them to.

OK, now, /observer/ over here is from Northwestern, and he has been elected as an honorary member--he doesn't have our--he doesn't have epilepsy--but, uh,=

Ob: =Well, several people have offered to give it to me.

/LAUGHTER AND JOKING COMMENTS/

1.30 S1: No, what it is is--Northwestern--Dr. /Workshop Director/ and /observer/, and a few other people, are working on putting together a little booklet--it'll be going out, hopefully nationally, to other=

Ob: =Definitely nationally=

S1: Definitely nationally?--uh, to other chapters, uh, and groups that are getting together, starting self-help groups like we've got going here, and to--so they can kind of put it together--is, they're taping everything we say, unless, there's something you want to bring up and you don't want it on the tape.

1.40 Pl: You tell--you say it. . .

You say, "Listen, I would prefer we turn off the tape for this little section--of what I want to talk about." In other words, that way, it will be private within the room. Definitely.

The stuff he's doing is just for, so that he--when--when we write it up in the book, it's gonna come out, what's gonna be needed, and what other people are gonna need to know about how to run a group and how not to run a group. OK, and, uh, possibly we'll come up with some ideas in this room that other people will be able to use when they start up a group, you know, in California, Washington, Kansas, Arizona, or whoever--you know, wherever. And if, uh, as I said, if you don't want this to go

1.50

A-3

any farther, he'll just shut it off. And if you want to, you also have the right to ask /observer/ to step out of the room.

What I'm saying is, if you just want to talk about people that have our problem, you can ask /observer/ to step out of the room. I don't think it's necessary, personally, 'cause, he's pretty sware of what the hell's been going on. He's been around here for, what, about six months? on and off?

- Ob: In the project? Six months, yeah. I've been coming here=
- 1.60 St: =Four=
  - Ob: =Yeah--somethin' like that.
  - J2: Seems like longer./LAUGHTER/
  - S1: And--uh=
  - Ob: =I'm treated with such respect, hey. /LAUGHTER/
  - S1: We love him.=
  - G3: =Well, that's part of being a member.
  - Ob: I know.
  - S1: Yeah, we tease each other like holy hell around here!=
  - G3: #And get on each other's back.
- 1.70 S1: Yeah, at times, sometimes, if we feel a person's feeling sorry for
  - P2: Kick him in the rear when he needs it!
  - S1: himself we'll tell him: "Stop feeling sorry for yourself and get
  - El: And he needs it!
  - S1: off your ass and take care of it!"--you know, but, I mean, things are constantly going on like this at this place and if it upsets you guys--something that is said one time--don't hold it against everybody. Come back again--after you've thought about what was said--and if you still think it's wrong, sit down with that person or those people or bring it up amongst

the group--how you think it's wrong--and ask them to think about what you've said, 'cause you've thought about what they said the week before. In other words, we try and help build each other's ego here, but sometimes to do it we have to tear each other apart.

E1: And shut some people up!

S1: That, too=

E1: =Yes! You get the hint?!/LAUGHS/=

P2: =Ed, leave the room! =

E1: =Shut up!=

1.90 S1: =You can't make me leave the room!

E1: Yes we can-we can vote on it! /LAUGHS/

S1: Now, do you guys have any questions? Either of you have any questions?

## Excerpt Two--February 1, 1979

- 2.1 S1: You wanted to say something?
  - 11: Yeah--I got, um, something to read here that I just wrote up.
  - S1: Oh, is that for the--uh=
  - Il: =No, this is something I wrote. The name of it is, um, I Am a Young Man. /READS/

I am ā young man who speaks, and writes, about how to achieve success.

I said, "Life is a challenge, but remember, you're the best.

Even I've failed to show progress."

I thought that there was no bigger word than compensation,

2.10 but I even learned a heavier word, it's called inflation.

Because now I am here with friends --

I'm the young man whose life soon will end.

/SILENCE/

(I can't hold it.)

I can't do nothin', though I try my best. . I was checkin' out what you were saying about the airport=

R1: =/117, f tell you, like I. . .

L1: =Well, now, what were you telling me downstairs?

II: That's what I said, "I'm a man who speaks, and writes, about

2.20 how to achieve success."=

L1: =Practice what you preach.

II: I've been practicing but I've failed to show progress.

Li: Keep practicing

When you fail you've got to keep trying and trying and try again. Do you hear what I'm saying?

- G2: You don't fail until you stop trying!
- Il: (unintelligible) a million times!=
- S1: =Bingo! He just gave you an answer. Say it again, will you \(\frac{1}{2}\)/.
- G2: You don't fail until you stop trying.
- 2.30 L1: That's true.
  - Il: When you fail more than a million times you need to quit.
  - G2:

    a million and one times!=
  - F2: =But I'm trying agair. . . I've been down a lot of times.
  - I1: I know that=
  - S1 =Huh?

- Il: I know that this world won't give nobody--that's in our state,
  you know, in out state of mind of--let's say--that has the thing
  that we have--a fighting chance, but, uh--I'm tired of fighting.
  I've been begging and then beg (unintelligible). . .
- You've got to keep fighting whether you like it or not.
  - S1: You don't think that what's been happening here, right now, has been good? We're all involved with you.
  - That's why I've been coming.
  - S1: 0K, so are you saying you're giving up?
  - ii: I gave up because even if somebody tried to help me, I'll still fail.
- S1: All right, so now what are you learning? Are you learning-2.50 are you still gonna come here? After that statement?
  - II: Yeah, I'm still gonna come.
  - Si: All right, because, all right, it took me a few weeks to get involved with this place. You've come, what, three weeks?

I1: I only came--this is my second week.

S1: This is your second week?

J1: You know we're not perfectionists=

Il: =Yeah=

J1: =We can only do so much.

S1: We're only human.=

2.60 J1: =You may, uh, I don't care how many times you may try, you can even go back to the same place and try, sometimes it's just who you talk to=

G2: =Thank you=

J1: =or how you're feeling at the time, or your attitude or their attitude--you know, you can't put all the blame on yourself.

Sometimes other people--with this weather and, uh, everything else--other people are going to get down in the dumps, let's say, and you go in , you look for a job or you try to do something--they can give you, uh

2.70 II: I ain't never been this far down.

L1: You always like to help other people out, but you're not helping yourself out, you don't have enough confidence in yourself.

 $\frac{I}{I}$  was

just going to say that.

J1: You've gotta tell yourself it's not always you. . .

F2: You come first. You come first, otherwise your g--

J1: Sometimes it's the other person at fault. Sometimes it's not you. I know a person-went in all the-all the scholarship-all the-everything out of college to get a job, they were

able-bodied, they were all right, no health problem, nothing-but they were turned down just because the boss at the time, uh, stubbed his toe or something, he felt, uh, lousy, he didn't even want to see the guy, but since he was, uh, he was

11: Scuse me, <u>/J</u>17.

J1: uh, that was his appointment to see him, then.

Il: They wouldn't even let me finish high school.

D1: But look, they didn't let me finish so I took the GED and went out.=

G2: There's a lot of people.

2.90 J1: =You can take a GED=

L1: =Yeah, that's nothing, you can still get it from here.=

II: I. . . J--Job Corps and i finished=

D1: So then you couldn't

G2: GEDI

P1: =H--Hold it! Hold it.=

S1: We're going--listen, now, I'm going to stop everybody, damn it,
I heard about what happened over the last few weeks=

P1: =I was taking it, /S17!=

S1: =and=

2.100 P1: =Go ahead.=

S1: it's, I don't like--apparently, you know, from what I understood from a certain gentleman, in Washington, I was--quote-- being viewed as the leader, and without me, apparently, it didn't go too hot. Now, OK, I thought about, maybe I should listen to those tapes and find out what happened. I decided, no, because I'd like to consider myself part of this group, not the man up there, looking down on all of you. I want to be down here,



but, damn it, when things get out of order, until a few other

people get the nerve to step in and say "Shut up and let the man

2.110 talk," that's when I'll step in. That's why I've been keeping

my mouth shut tonight, or I've been trying to. Now, he was

doing

Pl: Yeah, you were doing. . .

his talking. When he's done, then, one at a time, we'll come in--and run this thing so that everybody gets their word. Now, if you feel that somebody else is coming out of order, say, "Knock it off, let that person finish."

Don't always wait until I get so boiled that I do it.=

P1: =Hey! Listen, I was just about to say the same damn thing!
You know it, too.=

S1: =No I don't.=

2.120

2.130

Pl: =Yes, I\_was. . .

G2: Hey, let's not--look, look, OK=

P1: =I told you I was going to, you just don't remember,  $\frac{0K}{1}$ -hey,  $\frac{1}{\sqrt{S_1}}$ .

11: What I was saying

is, um, I wasn't actually giving up, it's just that—what the man was saying when he was here, he said, um, there's too many people around—and then again, um, my mother told me that, um, I should take a desk job—I can't sit down! I like to get moving, I like to build things, that's what I'm about—I like to build things, I like to build things 'cause I know I can do it.

G2: 'Scuse me, can I say wone word? Just one?

J1: No, wait 'till he's through .=

G2: =OK=

J1: =Go ahead, finish.

Il: When you know you can do somethin', ain't no way in the world somebody gonna keep you out of it, right? If you know you can--say, for instance, you know you can build a building and somebody say, "No, you can't do it. We're not gonna let you do it." That hurts, OK, and you try your best to conceal that--2.140 that pain, you know, you conceal it for so long and then suddenly it just busts out, you know, like now. I've gave up a lot of times, but I always came back, you know, I always came back with a left jab, you know, and it was strong. I always came back strong. But now, it done come down to the boiling point. you know, where I -- I never, you know, cursed, you know, the top man out, but, hey, somebody else tells me that. "No, you can't do this," again, and he's up there, got some thing down on the paper, on this application, saying that, uh, we won't 2.150 discriminate you for the defect that you have, and then he comes around here and stabs you right in the back. I swear

S1: Maybe.

Il: I'm finished.

I'll break his neck.

G2: It sounds to me as if -- in essence, what you're doing is contradicting yourself.

Il: Maybe so.

G2: But, uh, as far as success goes, the best thing in the world you can build up is #\overline{T1}\overline{7}, which is you. As long as you let \(\frac{117}{117}\) fall down like that building you're talking about, you'll never be able to build anything, including that building you were talking about. That's what it boils down to, because,

fG27 himself, believe me I--I know quite well what you're talking about. You spend your last nickel to go to college and they tell you you can't get a job because of your--your problem. In essence, you know, they beat around the bush, et cetera, but that's what it boils down to. You have to take it accordingly and work with it., The only thing you can do now is cope with it as it is, and hope for the best.

2.170 II: In other words, keep on dealing with it.

G2: Exactly. And hold a positive attitude towards the whole issue.

Ji: Can I say something?

G2: Sure.

2.180

J1:

J1: Did you get that GED that you, uh=

Il: =I went to Job Corps for it.=

J1: You did get the GED?

Il: I got my, uh, high school diploma.

J1: Yeah. . . well that's the thing, because you were saying that you didn't get it, because I was going to say they don't, uh, in Chicago, uh, they don't stop you from, uh, going to school.

Il: Oh yes, they did. They did stop me!

They may have before, but they don't now. They don't stop you now. Plus the fact--you were saying about, uh, building this house and everything. Have you--have you thought about what kind of a job you are looking for on both sides--on the employer's side and your side--whether he's looking out for you or his--the people that are working with him, or are you looking out just for Ira?

45

ii: Well, no, I'm--I never thought of it that-a-way, the only

part I thought about is that--I got to get out the house,

I got to do somethin', I can't just sit in the house all day.

G2: Yeah.

I1: I got to get into somethin', cause sitting in the house all day is boring.

Jl: But, see=

2:210

Il: =Letting your body go to waste.

J1: Yeah, well it's fine to get a job,

G2: Thank you.

- J1: gotta think--"What kind of a job am I best suited for? Will

  2.200 this job in any way hurt or afflict any other person? If I should have a siezure on the job, would I hurt other people or would my employer, uh, hold it against me? Whereas, another job I can handle--even if I have a siezure I wouldn't be hurting anybody but myself."
  - It: Excuse me but, wh, in maintenance, the way I was talking about, I was being a maintenance man myself, I mean, I could start out, you know, with just a screwdriver and a pair of pliers, and have something, even, you know, that's what I'm talking about, but--I know wood, OK, I know aircraft maintenance, I know general maintenance, you know--what is my downfall?

    What is holding me back?
  - J1: All right, for one thing, you're talking mostly about now,
  - Il: "That's what I'm interested in."
  - J1: =All right, now, if you go high enough and you're working for somebody else, don't you have a chance, if you have a stezure, to fall and break your neck? He'd be liable for your death.
  - II: No, 'cause, see, I know--I know better than that. I know that--

- I can't--my father already told me, "Don't go around places"-
  2.220 that I'm not suited for high places. But I could--I've did

  porches, I've did patios and--you know, but, I did that on

  my own time, you know, that was my money I was putting out,

  you know, and I was making my own money at the time. That's

  how I was doing it then. Then, I was my own boss, then.
  - J1: Yeah, but see, if you went to work for somebody else you wouldn't be your own boss and you couldn't tell yourself what kind of, uh, you were going to put in a porch when he wants a roof put in, see what I mean? You've gotta look at the company and what kind of work they do.
- 2.230 II: But the only thing I could say is "Yes, or No." If he asked
  me, uh, "Would you put this in?" the only thing I could say is
  "Yes, or No." Especially if it's a roof--and I know better than
  to go and mess with a roof. I know better. I won't.
  - J1: Yeah, but he might want some explanation.
  - It: The only thing he can have is, "NO," and "click." 'Cause he can't force me to do nothin', 'cause, see, at that time I'm my own boss.
  - J1: No, I'm saying that if you're working for another company=
  - Il: Oh, you're saying that if I'm working for somebody, and then, uh=
- 2.240 J1: Yeah. =He
  says, "Well, this is the job we have for you to go on, or this
  is the job we have to do right now."
  - Il: Well, that's the same thing.=
  - J1: =No it's not the same thing=
  - Il: =Yes it is, 'cause I'm not going to conceal my epilepsy, especially

I'm on a construction job. I'm not going to conceal it.

I'm not going to conceal it or anything.

- J1: Yeah, and this is what I'm saying--construction jobs usually won't let in an epileptic because they feel they can hurt themselves and hurt others on the job.
- Il: That's weird, 'cause, I mean, uh, hey, we still got our hands, we still got our eyes, we still got everything.
  - J1: Yeah, but we still have our siezures, too, and we--a lot of us don't know when we're going to get them--or where.
  - G2: /11/, I think what she's making reference to is mutual consideration.

    In other words, although you can do these things, would you want
    to do this, to put this, I mean, and at the same time=
  - I1: =jeopardize myself=

- 2.260 G2: jeopardize yourself and someone else who might be your friend.
  - II: No, it's just that I don't like to sit around the house and. . .
  - G2:

    I agree with

    you a hundred per cent, but I also agree with what Jan's
    saying. You can't jeopardize your friends.
  - Il: I just can't stand it.
  - G2: There's a way around it. You gotta keep looking--believe me.
  - Il: I can't do kitchen work.
  - G2: Well, this is -OK, what I'm saying is, there is a way around it.
  - Il: Would you do me a favor?
- 2.270 G2: You know what--instead of the "I can't do," you know what
  you emphasize--"I can do." And I'm sure you'll find something



that fits right in with your-

- J1: "In other words, I'm saying, don't reach for the moon. Stay to the ground.
- S1: What you gotta do sometimes is, you gotta start out at the bottom level--get a job.
- Il: You've got to crawl before you can walk.
- S1: That's right.

## /INTERRUPTION -- QUESTION REGARDING PHONE LIST/

- Il: Well, I was trying to say the same th--if you keep giving up

  2.280 on yourself like that, same thing, you're putting yourself
  down, and you were telling me downstaris, just the opposite.
  You were trying to give me confidence when I was feeling depressed,
  and then here you are telling me just the opposite. You're
  trying to build everybody else up
  - II: Including myself=
  - L1: =and you're not even trying to help yourself. You've got to practice what you preach. You've got to think about what you say, and do it.
  - J1: In other words, don't be two-faced. /LAUGHS/
- 2.290 L1: Think about what you tell other people and then think about trying it yourself.
  - Il: Yes, ma'am.
  - G2: Excuse me,  $\frac{\sqrt{S1}}{I}$ . The new gentleman has something he also wants to say to  $\frac{1}{I1}$ .
  - F2: /Il/--just keep on plugging, 'cause I'm in the same boat
    you are, man. And I have to plug--you see, you're in a better
    boat than me, you see, I have another problem. I'm afraid of
    walking, and I have two good legs; two strong



legs. I'm afraid of walking, without some type of psychological crutch, you see. So you're in better shape than me.
So keep on plugging. Keep positive--because I'm getting there;
I'm gonna get there.

- S1: You two might be able to get together later on.
- G2: You know something. Someone told me one time, if you know you're a quitter, you'll never win, and if you know you're a winner, you'll never quit. And if you analyze that, in essence what it's saying is, in spite of what happens, tomorrow's coming. Give it another shot, that's all, like the gentleman was saying.
- 2.310 F2: Give it another shot, 1117.
  - Li: There's a lot of different kinds of work, a lot of different jobs you can try. You might not think you'll like it, but if you try it, you might find you'll like it.
  - S1: In other words, the same thing I was just saying to /R1/ a little while ago. Now, have you got anything you want to say about /senior EFA staff member/, or what's happened to you in the last, I haven't seen you in what, five weeks?
  - L1: It's because of the rotten weather, I wouldn't step out the door.
  - S1: You don't want to say anything?
- 2.320 L1: Well, not right now .=
  - $S1: = /\overline{P}1/?=$
  - P1: =I'm just sorry about the way he's feeling about himself.
  - S1: We'll get him up. We'll get him up--or he'll get himself up.

    Believe me, we'll kick him in the ass when need be and where

    need be. /LAUGHTER/

- Il: Yeah, she told me something I was doing, you know, downstairs, telling her to be confident, and here I am feeling bad about myself.
- S1: Well, maybe you guys are giving each other a little kick in 2.330 the ass when need be and where need be.



## Excerpt Three--February 22, 1979

- 3.1 S1: All right, you should be listening to this especially, /P27.
  - P2: I already am. /LAUGHTER/ /S1/, I already am. Buc it doesn't stor me to try again.
  - S1: All right, do you understand what I'm -- why I'm asking her these questions on what she does?
  - P2: Yes, I'm hearing you.
  - S1: I'm asking her because I, you know, remember what happened to you--you hadn't checked out the audio--so=
  - P2: =Well, I never--I haven't been on a train for six years.
- 3.10 S1: All right, well, now you have. Now you know, you have an idea about what you've gotta check yourself out for, before you get on the el. Understand? 'Cause she's just checked, she checked herself out first--/Ll/ and I had talked about this--about, what, three weeks ago?
  - P2: No, but, \( \frac{\slim}{\slim} \), I had such a --I felt fine before I got on the train. I was doing it because I was a blind individual, not because of my epilepsy, and--I was tired, you were tired, \( \frac{\slim}{\R27} \) was tired. And I wanted to go home, I wanted to ride it for a change=
- 3.20 S1: =Uh-huh=
  - P2: =of pace, not bec--everything--I didn't do it because of my
    friends and because of my epilepsy or anything like that-I did it for myself, to expand myself as a blind individual.
  - S1: All right, well, what I'm saying is, maybe, before you do it again, you'll, shall we say, you know, check your own--Do you keep records of when you have siezures?



- P2: I do pretty well.
- S1: All right, well, you know, I've got mine down to the point where
- I know that if I'm going to have one it's gonna be within four
- 3.30 hours after I wake up--OK, because I've been keeping records.

What I'm saying for you is, before you ride the train--is, all

right, you know, I don't know what your records are, but what

I'm saying is you check--OK, did I get enough sleep, have

I taken my medicine

P2: I had enough sleep the night before--I had enough sleep.

S1: All right, was

it because you came to the group, did that cause a little tension which could have, uh, caused the siezure?

- P2: You saw that after the meeting I was fine, /P1/ and /R1/ and I were doing b--my old neighborhood. /G2/ went over and sat and talked to /R2/. I was fine.=
- S1: =All right, well, what I'm saying is have you-have you checked
- P2: I was fine.
- S1: into it. You know it. . .
- P1: The possibility that you-- that you might have been a little bit excited even though you didn't realize. . .
- G2: Subconsciously excited is what she's in reference to.=
- P1: =unconsciously excited=
- S1: =That's what I'm saying, you know, check it out and (unintelligible)
- 3.50 P2: And it could

be possibly because of my extra-sensitive hearing.

S1: Possibly, yes.

E2: There's more than one reason.

S1: I mean, I'm not a doctor. I'm just going over things that I've checked out! /L1/, you know, and I talk a lot and /L1/'s checked out now--and I think I've talked to a few other people=

before I went up on that platform, she said "Are you ready?"

and made sure. I said "Yes," 'cause I was well-rested enough

when I got on--I felt I did fine coming down--I was a little

dizzy, but I handled it pretty well. OK, then when I went home

with you and /R2/ I was fine, I was just--just as much as you-
you were tired, /R2/ was tired, I was tired, we all were beat-
we got out of the meeting very late. OK, it was about 9:30,

quarter to 10=

S1: =Yeah, all right, so what I'm saying is, because we got out so late and we were all tired, maybe that's what it was-
the extra noise, with your extra amount of hearing--this-maybe that's the reason why you had the stezure after all.
You understand what I'm saying? You're not following me, right?--No--all right, what I'm saying is, OK, when you came down, you didn't have a stezure coming down, did you?

P2: No.

S1: Ok, but you were tired going back. You were tired

P2: But I was responding--

you saw me responding to everyone on the train.

3.80 S1: Yeah, but remember you--you had. . .

P2: We were having a discussion.=



- S1: =Remember you had the aura and I tried to get you to get off at Fullerton, you refused.
- P2: Because I /SIGHS/ I wanted to try.
- S1: Yeah, all right, but the . . .
- J2: It's because you're stubborn.=
- P2: =No! I wanted to--No, I wanted to try a little longer. It was my first time in six years, Jan. I wanted to try!
- J2: Well, I'd just say--
- 3.90 that--a lot of--<u>I'm</u> stubborn--and you're saying...
  - It wasn't because I was stubborn.

    It was because of my blindness, because it was expanding me.

    I was expanding my independence so that—that the self-help group did not have to rely—or I wouldn't have to rely on anybody in general!
  - S1: Good! Good! That's all the better that you don't have to rely on everybody, but what I'm saying is because of what happened that night, if you take the train again and you start feeling down, will you think about getting off the train for a little while and relaxing so that you don't have a siezure.

    J2:

    Because that's--just because

you get off the train doesn't mean you have to stay off it.=

S1: Yeah--I mean, just get off for a little while and relax for a little while and then get back on the next train--and-I'm just suggesting, you know, when we went home the other night, you know, if you feel that way, and you're on the train, you'll get off at the next stop, wait for a while 'til you feel better, then you can get back on the train,

7-66

and go. Now, if you're not tired, which is obviously one of the

things that may have caused the siezures later on that evening,
if you're not tired, then you probably won't have to worry
about it either--in other words, you have to, you know, kind
of--like I do, I keep a rec--of, you know, I kind of figure
out, all right, am I up for a siezure today, or am I not,
because I figure out what's been happening in the last two
or three days--have I forgotten to take my medicine? Have I
had enough sleep? Like, I had a siezure--what was it, last
Friday?--I knew I was going to have it, 'cause I had forgotten
to take my medicine on Thursday and--Thursday night, I was

up late--so I was expecting one last Friday, and sure enough,
I had three of 'em.=

L1: =Three! ? God!

E1: Can I ask a couple of questions? OK, now, you say--get off the train--why? I mean, she still might have her seizure off the train-

S1: =That's true.=

E1: =but she's surrounded by some men.

B3: That's true--but--um--excuse--um--what you--

P2: Neither way I lost that night,

3.130 anyway! So Whoopee! So whoopee! I'm not going to quit. I'm

E1: OK, but I mean (unintelligible)

P2: not gonna quit!

S1: I'm not saying you should quit. I'm just giving. . .

L1: There are so many

more metal things on the track--on the train.

S1: a suggestion, if you feel, if, shall we say, a form

of aura. . .

P2: I have auras all the time. I know what my auras are.

S1: That's all I'm saying is, all right, if you're on the train

3.140 and you have an aura like you did that one night, think about getting off for, maybe ten minutes, and catch. and catch.

P2:

You want to

help me try and find the--try and locate where the next train

is. I don't understand 'em. D'you understand?

S1: I'm sure, you know, when I, when you're going to take a train, you know, a couple of us that live in the same area, you know, we'll, you know, when we go home, we'll take you with us.

P2: NO! What I'm saying is--

3.150 G2: =I think what she's making reference to is what she just said;

in the event that she should be alone, alone-with herself, then

Yeah.

G2: the ultimate challenge is there.

S1: OK, then, what I'm saying is, OK, before you get on the train in the first place, you figure, how do--how was I for the last couple of days? Have I had my sleep? Have I had my pills? Have I had any auras? I'm thinking, you know, what I'm saying is, before you get on, think, what's it been like for the last day or two?=

3.160 E1: Uk--excuse me. . .

J2: Don't you live on the north side? Right? OK=

S1: She lives up near  $\overline{/G27}$ .

Pl: But she's also talking about -- for the other six days, too.

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J2: That's what I'm referring to, and after a certain, certain hour,
      you know, all the trains stop at all the stops, correct?
S1: After 8:00.=
     =8:00, OK--and. . .
                 I--like I said--i don't understand the trains--
P2:
      the night that \frac{\sqrt{S17}}{2} and \frac{\sqrt{R27}}{2} took me on was the first night
     in six years. I do not understand!
     OK, what do you do in the same situation?
P2:
                                       What do I do? W. . .
J2:
                                                      Well, well, just
     let me finish!!
P2:
            What do I do you're asking me is
J2:
                          No. We got the trains, OK=
G2:
     ■Patty=
     =No, she's gonna ask me what I do, wh=
```

- G2:
- ≖Let her ask her question.
- 3.180 P2: if I don't have the trains.=
  - =No, that's not what I'm saying.
  - P2: OK, then, go on=

- =Let her ask her question. G2:
- P1:
- J2: =OK, let's say that you were walking, OK--um--and--you're walking I don't know how many--um--blocks, and you're not sure, uh, which street is which=
- h I don't in the winter.
- J2: OK, how do you get to the right place?
- 3.190 P2: If there's an individual, I ask.
  - J2: OK. . . /TAPE SIDE ENDS/

G2: . . . that there's no one on a particular car, once you get on it, depending on the time:=

P2: That =That's right. I'm just saying for a precautionary.

G2: It happens.

J2: There's also--usually--at least a conductor that comes walking through, OK=

P2: =I didn't know that!=

3.200 G2: =I'm not aware of that situation.

J2: Especially when only one person gets on the car.

'Cause I've been on trains before and I've been...

P2: OK, that's you! THAT'S YOU!=

J2: =No, that's

P2: THAT'S YOU!!=

S1: =Wait a minute !=

P1: =Hold it!=

P2: =That's You!=

 $s1: = \sqrt{P27}! =$ 

3.210 P2: "That's you!"

B3: =No, that's all of us=

G2: =Come on! Come on, we're not gonna get overemotional about theissue--i('s just. . .

J2: <u>P27</u> It has nothing to do with me, OK, I'm just telling you that they may do this for other individuals, OK. I've been on trains before, and I've been the only individual in the car, and the conductor has asked me to move to another car. OK. . .

G2: Well, I've been the individual on a car and the conductor

- 3.220 has just taken me home, period. I didn't see him until I
  get off and wave bye-bye at my stop.. It's be n--I mean-homestly=
  - J2: Then again, I've yet to ride the Howard trains and be the only one—the train, I'm talking, whether 5:00 in the morning or 3 in the morning, you know—it—it doesn't—I'm not saying it's not going to happen, I'm going to say the probability is very low of you're being the only one. I think that you'd be much safer taking the train and askind someone—"Hey, is this the right stop?"—on the platform. Listen,
- 3.230 nobody is going to do anything to you with a dog=
  - P2: You wanna make a bet?! You wanna make a bet??!!
  - G2: I don't agree with that.
  - P2: YOU WANNA MAKE A BET??!!=
  - S1: = <u>/P2/</u>, if you're gonna scream and yell, and not listen to what we're talking about=
  - P2: =I hear it!=
  - G2: =OK, /P2/, don't worry about it, but--but. . .
  - P2: I hear it!
  - P1:  $\frac{7}{1}$  don't get yourself=
- 3.240 S1: =We're on your side; you know--remember--just before--at the--
  - G2: Lhat's what I'm saying, you're getting uptight now, come on.=
  - S1: =first thing we talked about, we come up with ideas for everybody else.
  - G2: I'm in contrast to what was just said.
  - $\mathbf{E}1:$   $\mathbf{\overline{Z}}\mathbf{S}\mathbf{\underline{\overline{Z}}}\mathbf{7}$ 
    - /G27, one at a time, please.=
  - Pl: =Yeah!=
  - G2: =6:, 1'm sorry, excuse me. Go ahead,  $\overline{P27}$ . .  $\overline{\overline{J27}}$ , what

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If you--if you--can--I mean--I_
3.250
                                          I can prove you -- things that my
        P2:
                                                                        OK
        J2:
             dog and I, when we're even together what happens to me!
        P2:
                                                               Get to the point.
        E1:
        P2: Like the day I was released from the hospital, in January the
             11th, the night, I got raped! I can tell you, that the thing
             is, even though my dog is--uh--only can do so much and I can
             do only so much! Now, as a blind individual, and has been
             sighted, I can better, bet -- understand from both sides of yez --=
        G2: =I'd agree.=
3,260
             =But you have to try, /P27.
             I am trying!=
        P2:
             =This is what I'm making reference to.
        G2:
             OK, I. . .
        J2:
                 I am trying!!=
        P2:
        J2:
             =I mean=
        S1: /P27, all we're doing is giving you a few suggestions on some
             things that you might want to try to make it easier for you.=
             =Yeah, and I've accepted your suggestions long ago.
             OK, all right.
3.270
        P1:
                 All right, then we've misunderstood you, and you misunderstood us.
        $1:
        P1:
             I guess we didn't realize that you had accepted our advice--
             I mean, it's up to you to decide if you're going to use them
             or not, or come up with your own ideas -- but we misunderstood
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each other--because to us, I--I think  $1/\overline{3}2/\overline{1}$  will agree with me,

you were disagreeing with everything we--we were coming up with.

G2: <u>IP2</u>, don't get yourself over-emotional about this issue, OK?

E1: I just--wanna

3.280 ask one last question.

S1: Go ahead.

El: OK, Steve made mention about, uh, psyching yourself out whether you've had enough sleep and all this stuff, right? OK, what-why? I mean, when--if you feel an aura or something else coming on, I know for myself, if I feel something like that, I don't think about that--I think of something pleasant--like--I forget everything else.

P2: That's what I was doing that night!

E1: I don't think about my problems--'cause you work yourself up. . .

That's what I was doing that

night--like what <u>/El/</u> was saying--I was just--like when you asked me to get off at Fullerton, all I wanted to do was try a little longer to keep thinking of the pleasant--that we were all discussing--you and <u>/R2/</u> and I were kidding around--OK--that's what my head was more in tuned of.

S1: All right, well, now what I'm saying is, you know that maybe next time.

J2: Is there--uh--is there

a point though, OK, I know there is with me, OK=

P2: \*Everyone that is sighted has their limitations, everyone!

3:300 P1: Will you two cool it!