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## Factors that influence the development of supports among adults with developmental disabilities

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FACTORS THAT INFLUENCE THE DEVELOPMENT OF  
SUPPORTS AMONG ADULTS WITH  
DEVELOPMENTAL DISABILITIES

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Kathleen Susan Brown

June 1994

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6-12-94  
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## ABSTRACT

The development of natural supports and circles of supports for adults with developmental disabilities is a new focus and mandate from the state legislature for the Regional Centers in California. It is believed that this will enhance the quality and security of life for people with disabilities. The programs contracted with Inland Regional Center for independent living skills training have started to provide training in the development of natural supports and circles of support to the clients they now serve. It has not been known what characteristics or factors might be significant to the successful development of these supports.

This study surveyed Inland Regional Center case records of 45 developmentally disabled adults who were receiving training from an independent living skills training program and a new pilot program. The data collected summarized and correlated characteristics in relation to the development of supports.

This study identified factors that influence the development of supports among some of the clients that Inland Regional Center serves. Awareness of these factors may allow the Regional Center administrators to make more informed decisions regarding the development and funding of programs. It may assist case managers in client assessment and case planning.

## ACKNOWLEDGMENTS

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## INTRODUCTION

### Problem Statement

Regional Centers are social service agencies which contract with the State of California to serve persons with developmental disabilities. Developmental disabilities, as defined by the State of California Lanterman Developmental Disabilities Services Act (1976), include: mental retardation, cerebral palsy, epilepsy, autism, and a condition similar to mental retardation that requires the same treatment. The condition must originate before the person reaches the age of eighteen, be expected to continue indefinitely, and constitute a substantial handicap for an individual. The majority of the clients served in the Regional Center system have a diagnosis of mental retardation, which constitutes "significantly subaverage general intellectual functioning, an IQ of 70 or below, accompanied by deficits in adaptive functioning" (American Psychiatric Association, 1987).

Recent legislation (Senate Bill 1383, McCourquodale) requires that all Regional Centers purchase services which will assist clients in developing "circles of supports" and "natural supports." A circle of support is defined in the legislation as: *"...a committed group of community members...meeting regularly with an individual with developmental disabilities in order to share experience, promote autonomy and community involvement, and assist the individual in establishing and maintaining natural supports."* Natural supports are defined in the legislation as *"...personal associations and relationships typically developed in the community that enhance the quality and security of life for people..."*(Senate Bill 1383).

Inland Regional Center, serving San Bernardino and Riverside Counties, is complying with the new mandate in several ways. The administration



decided that a critical need for change was in the focus of independent living skills training, which the Regional Center funds. They are requiring these programs to include in their training the development of natural supports and circles of support. In addition, the agency has sponsored a pilot program to provide the training to additional clients. The agency does not have any data on what factors are significant and correlate with the successful development of a client's circle of support and of natural supports in the community. Data of this nature would assist in policy planning decisions.

### Problem Focus

This will be a positivist-correlational study and will focus on the issue of training adults with developmental disabilities to develop circles of support. Since this is a new mandate and focus for the agency, there is no current data available that indicates what specific factors play a role in the successful development of circles of supports. The current state-wide client assessment tool (Client Development Evaluation Report) does not specifically assess a client's potential for community integration, current natural support system, or family support.

The research question is: what factors facilitate or influence the development of circles of supports? The study will attempt to identify factors and characteristics that are present in clients who have obtained natural supports and possible barriers for those who have not. It will address the administrative and direct practice role of the social worker. The results will assist the administrators in decisions about the focus of program development and ongoing programs. It will afford some knowledge about the relationship of clients' characteristics and natural supports to the case managers at the agency. This will assist in assessment and case management decisions in the

consideration of training programs and independent living.

### LITERATURE REVIEW

No studies were found concerning the factors or characteristics of clients that are successful with the development of circles of supports. There is literature available about the concept of circles of support, which was developed by Judith Snow and Marsha Forest in Toronto, Canada in 1980 (Mount et. al, 1988). A model program in Connecticut began in 1987 and used this concept. A year and a half later, the program had helped to form 25 circles of supports (Mount et. al, 1988). Mount et. al define a circle of support as "...a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (page 3). They describe members of a circle of support to be "...usually friends, family members, co-workers, neighbors, church members, and sometimes they include service providers" (page 3). The definitions of circles of support will vary slightly as well as the way that they are interpreted. The most important factor, however, is that people with disabilities need support from other people besides paid service providers and that their quality of life will improve the more "normalized" their life style becomes.

The needs of persons with developmental disabilities were reported in a state-wide survey in New Hampshire. According to Edward P. Burke (1991), Director of the New Hampshire Developmental Disabilities Council, "...the greatest single need reported by people with disabilities and their families...was for companions, friends, for community connections." Because the focus of independent living skills training has been on activities rather than relationships, individuals with developmental disabilities are still very isolated (Amado, 1993). Results of a national study showed that 42% of persons

residing in residential care had no friends, even among other residents or staff (O'Brien & O'Brien, 1993). A study of individuals with mental retardation over the age of forty, showed that persons living with family members had less friends than those living in community residential facilities (Krauss & Erickson, 1988). Not only do persons who have developmental disabilities have very few friends, they generally do not regularly participate in activities with persons who are not disabled (Amado, 1993).

Only a small percentage of individuals with developmental disabilities live independently: in 1983 the frequency was 7% in California (Lozano, 1993). Many of those who do live independently receive independent living skills training from programs paid by public monies. Results of a seven year study showed that individuals who received greater amounts of independent living services were more likely to maintain their independent living situation. In addition, it was found that the living skills instructors not only taught critical living skills but helped the clients establish relationships and connected them to neighbors and community members (Lozano, 1993).

Establishing relationships, however, is seen as a problem for those individuals coming out of congregate settings and who do not already have family and friends acting as natural supports. One factor is the complexity of today's communities. The generic resources in the communities and community members alone are not yet seen as providing enough support necessary for individuals to live on their own (Catellani, 1993). Society tends to assign responsibilities for assistance to the disabled to special entities which could include the Regional Centers, the Department of Rehabilitation, and organizations like Easter Seals (Momm & Konig, 1989).

Complete community integration of people with disabilities is a quality of

life issue as well as a rights and moral issue (Rubin & Babbie, 1993; Sailor 1989). The extent of integration may vary according to the attitude of community members and their acceptance of the idea that individuals with disabilities should not be segregated (Momm & Konig, 1989). People with disabilities, because they are labeled, are excluded from the power and protection of community life (Reidy, 1993). Relationships, however, are transactional. Community members can benefit from getting to know individuals with developmental disabilities. Relationships can be anywhere from casual acquaintances to the development of deep friendships. Surrounding a person with a disability with community members affords that person broader growth experiences and establishes mutual appreciation and interdependence (Batholomew-Lorimer, 1993). Friendships and relationships are very important for everyone; they are at the "heart of existence for all people" (Amado, 1993).

#### PURPOSE OF THE STUDY

Since there is very little research in this area, this study will explore the characteristics and factors that are present among individuals with developmental disabilities who have shown success in the development of circles of support and natural supports.

The research question is: "What factors correlate with the successful development of circles of support and natural supports among persons with developmental disabilities who are receiving independent living skills training?"

Based on the previously mentioned study (Lozano, 1993) which evidenced a relationship between the amount of independent living skills training and the maintenance of the person's independent living along with the side benefit of connecting the person with the community, the following hypothesis is being made: Clients who have received independent living skills training for longer

lengths of time will have developed more natural supports and community connections than those clients who have received less independent living skills training over a shorter length of time.

## RESEARCH DESIGN

### Sampling

In two different programs, over 120 Inland Regional Center clients were receiving independent living skills training at the time of the study. Because of the new legislation and mandate, each program is being required to provide training in the development of circles of supports and natural supports. One program, a pilot program started in April 1993, served a total of twenty-eight clients. All clients in this program were funded for twenty-five hours per month for usually a maximum of six months. The training emphasized the development of circles of support along with some skill training and was intended to be intensive (25 hours per month) for a one-time period. The study sampled twelve clients from this program ( $n=12$ ), three clients from each of the four independent living specialists who are providing this service. The other program, an independent living skills training program, has existed for over ten years, with over one hundred clients receiving training. Hours of service varied from four to sixty hours per month per client. Many clients in this program have received a minimum number of hours for many years to maintain their skills and independent living situation. This program has used the independent living skills model ever since it began and just started to include the concept of circles of support in their curriculum. From this group, the researcher took a stratified sample of thirty-three clients ( $n=33$ ). A list of all clients was made which divided the clients according to the hours that they were receiving. Every-third client was chosen from the list, starting with number one. Total sample number

was forty-five.

The criteria for the selection of all clients in the sample was:

1. have a diagnosis of a developmental disability
2. be an adult
3. be a client of Inland Regional Center
4. be receiving independent living skills training from one of the two

vendored independent living skills programs.

#### Data Collection and Instruments

The positivist paradigm was chosen over a more qualitative paradigm because, due to cognitive deficits of the clients, it would be difficult and time-consuming to obtain accurate information from in-depth interviewing. The regional center has a client file on all clients being given independent living skills training in two counties. The file provides an avenue for obtaining valuable information that is helpful in discovering variables among these individuals.

Data were collected by reviewing the agency's chart on every client in the sample. The researcher developed a *natural/circles of support survey* form (see Appendix C) which was used to collect the information from the chart. The form recorded client demographic information such as age, gender, and city of residence and other variables such as number of years received independent living skills training, number of years lived independently, in what independent living skills program they participated, diagnosis, and current living situation. Some additional information was taken from the Client Development Evaluation Report (State of California-Health and Welfare Agency, DS 3753, 3/86). This report is mandated by the State of California and is used by all Regional Centers. It is a well-tested instrument used by all California Regional Centers to

assess the client's functioning and identify need for programming. Social, behavior, cognitive, and emotional scores were taken from this report in order to discover what client characteristics might be correlated with the successful development of supports.

To get a measure of the successful development of circles/natural supports, the researcher developed a *natural support/circles of support assessment* form (see Appendix B). This form had never been used before. Input for the development of the form was obtained from each program and from the Inland Regional Center Director. The form was completed by the instructor for each client in the two programs and measured the number of supports the client has in the form of family, friends, community members, and paid providers according to the tasks most required to live independently. There are a total of fourteen tasks on the assessment form. A list of possible community providers and paid providers (see Appendix D) was also sent to the two programs to help with consistency in completing the assessments.

### Method

This study was a one-shot design. The independent living skills programs sent the natural support/circles of support assessment reports to Inland Regional Center and they were filed in the client chart. The researcher completed a one-time chart review, using the natural/circles of support survey form on every client in the sample. If information was not complete in the chart, the researcher contacted the independent living skills instructor and/or the client's case manager and recorded the information on the form.

The independent variables were the independent living skills training and other selected variables. The dependent variable was the successful development of circles of support and natural supports.

### Protection of Human Rights

The sample lists and the natural/circles of support survey form indicated the client by the state-assigned number only. No name was collected on the form or anywhere else. This insured the confidentiality of the clients in the sample. The completed forms are kept in the agency's file room until such time as they can be destroyed.

Inland Regional Center administration was in full support of this study and gave written permission to access the case records.

### Data Analysis

Data were analyzed using "SPSS/PC Plus," a data analysis software program designed specifically for research and statistics. Frequencies for all samples were obtained. The chi square statistical test was used to compare categorical data. The t-test was used to compare group means of ordinal, ratio, and interval variables. The Pearson correlation was used to test for linear significance of ordinal and ratio level variables.

## RESULTS

### Demographics

The clients in the sample ranged from age nineteen to seventy years. Forty-four percent were between the ages of twenty and twenty-nine. The mean age was thirty-five. Seventy percent of the clients lived in a medium-sized city (50,000-100,000). Over half of the clients were Caucasian, twenty-six percent were Hispanic, and about nineteen percent were African American and other (see Figure 1, Appendix E). The male/female ratio was forty percent to sixty percent (see Figure 2, Appendix E). The majority (89%) were single. Over half of the clients were living alone, while twenty-five percent lived with a roommate



or spouse. Twenty percent were living with a parent or other relative (see Figure 3, Appendix F). Over forty-six percent of the clients were involved in a supported work program, while thirty-eight percent had no program at all (see Figure 4, Appendix F). Gender statistics are as follows. Males: Fifty-six percent were in supported work, 6% were in a work activity program and 39% had no program. Females: 41% were in supported work, 22% were either in work activity or another supervised program, and 37% had no program.

The cognitive level of the majority of the clients (75%) was at the mild mental retardation level (see Figure 5, Appendix G). There were no clients who had a diagnosis of autism and three who had a condition similar to mental retardation. Twenty-two percent, however, had epilepsy and 17% had cerebral palsy (see Figure 6, Appendix G).

The presence of mental health disorders among the sample ( $n=45$ ) was 11%, although thirty percent of the clients in the sample were taking antipsychotic medication. Nine percent of the clients in the sample were diagnosed with a medical condition. Eighty percent of the clients had neither a medical condition or mental health disorder.

### Skill Levels

Scores taken from the Client Development Evaluation Report showed the following results.

Communication: The majority of clients were able to engage in either basic or complex conversation and had speech that was easily understood.

Cognitive: Almost half of the clients in the sample could read and comprehend simple sentences. The rest were able to read and comprehend simple words.

Social: Forty-four percent initiated interactions in familiar situations and an additional forty-four percent initiated interactions in unfamiliar situations as well. Over seventy percent of the clients initiated and established friendships. Over half of the clients engaged in social activities without encouragement and about thirty percent needed some encouragement. The majority adjusted easily to changes in social relationships.

Behavior: Almost sixty-five percent of the clients in the sample had a zero Franklin Factor (*ff*) behavior score, which means they have no behavior problems present. Over twenty-five percent had very low scores which ranged between one and seven, an indication that there are very few behavior problems present.

In summary, the majority of the clients in the sample had characteristics and skills that would indicate an ability to establish relationships which would help them form a circle of support.

### Independent Living History

Eighty percent of the clients in the sample were living independently, either alone or with a roommate or spouse (see Figure 3, Appendix F). The range of time living independently was from one month to nineteen years (see Figure 7, Appendix H). The mean number of months living independently was 51 months for the entire sample.

Because the two programs were very different, with different projected time-lines and objectives, frequencies were run to separate the groups and test for any significance. More of the clients in the independent living skills training program were living independently (88%) than the clients in the pilot program (49%). In addition, they had lived independently much longer (mean=60

months) than the clients from the pilot program (mean=27 months). As assumed, the newer pilot program had more clients living with their parents than the older, established independent living skills training program.

#### Independent Living Skills Training:

Over thirty percent of the clients in the sample had had no prior independent living skills training before the time period sampled (see Figure 8, Appendix H). The mean number of months of prior training for the entire sample was 26 months.

The hours of training per month per client varied from four to sixty. All twelve clients from the pilot program received twenty-five hours per month. There were fifty-one percent of the clients who had received between four and ten hours of training per month. The mean number of training hours a month for the entire sample was 15.4.

#### Supports

The supports measured included paid providers, community providers, family support, and support from friends. This data was obtained from the natural support/circle of support assessment form.

Paid providers: These persons would be either the independent living skills instructor or another person paid to assist the client such as a personal attendant, Regional Center case manager, or job coach. This type of support is not considered to be "natural." The number of paid providers for the sample ranged from zero to thirteen. The data analysis revealed an average number of 4.7 paid supports. Twenty-two percent, however, had none.

Community Supports: This source of support would be people in the community that are available for the entire population and are not necessarily

paid to help a person with a disability. Examples would be bank tellers, ministers, community recreation leaders, and apartment managers. These are natural supports. Over 40% of the clients did not receive support from any community providers and only 20% had one source of support from the community. Twenty-nine percent had between two and four. The average number of community supports for the sample was 1.6.

Family Support: This category would include parents, siblings, and other relatives that are available to either directly assist the client or provide guidance. These are also natural supports but have typically been the only non-paid persons in the past that have been available to assist the client. The number of family member supports for the sample ranged from zero to fourteen. The percentages varied with the mean number being 5.4.

Friend Support: Friends could include a client's disabled or non-disabled friend or possibly a neighbor with whom the client had developed a friendship. This is considered to be a natural support. Friends that provided support ranged from zero to eleven (mean=2.3). Almost sixty percent of the clients had possible supports from one to four friends. Thirty-one percent of the clients had no friends that could assist them with tasks.

The number of total natural supports (community, friend, and family) ranged from one to eighteen (mean=9.2). The data show that, overall, the clients in the sample had more natural supports than paid supports (mean=4.7). Of the natural supports, more support came from family (mean=5.4) than from community or from friends.

#### Factors Influencing Circles of Support

Three variables had a significant relationship with the development of

circles of support and natural supports: gender, living situation and the presence of epilepsy.

Females had significantly more family support (mean=6.4) than males (mean=3.8,  $t=-2.22$ ,  $p<.05$ ). Although not statistically significant, females tended to have more friend support (mean=2.8) than the males (mean=1.5,  $t=-1.97$ ,  $p<.10$ ). Males had more paid supports (mean=6.7) than females (mean=3.3,  $t=2.61$ ,  $p<.01$ ).

There was a tendency for clients living with their parent to have more support from friends (mean=2.3) than those who lived alone (mean=.9,  $t=2.0$ ,  $p<.10$ ). Clients living alone had significantly more paid supports (mean=5.2) than those who lived with their parent (mean=1,  $t=4.23$ ,  $p<.01$ ).

Clients without epilepsy had more community supports (mean=1.8) than those with epilepsy (mean=.6,  $t=-2.32$ ,  $p<.05$ ).

There was a positive linear correlation between the amount of time receiving training and the length of time living independently. The Pearson correlation was moderate ( $r=.64$ ).

Correlations between total natural supports and reading, language, clarity of speech, behavior, adjust. to change, social interaction, social activities, establishing friends, independent living, prior training, and age were tested but did not show any significance (see Appendix I Table 1).

Correlations were also computed for prior training and independent living history with paid providers, community supports, support from friends, and family supports. There was no significance shown (see Appendix I Table 2).

The presence of a mental health disorder and of mental retardation was tested for significance with the dependent variables. There was no significance found in either of these variables (see Appendix I, Table 3).

There was a total of seven clients in the sample who had a diagnosis of cerebral palsy. Their mean number of total natural supports was 7.7. Those clients without cerebral palsy had a mean of 9.5. The difference was not significant.

The total number of natural supports for clients who participated in supported work ( $n=21$ ) was compared to those clients who were in work activity programs ( $n=5$ ). There was very little difference found between these groups. The mean number of natural supports for those clients in supported work was 9.5; the mean number for those in work activity was 9.4.

Although clients with epilepsy showed less support from the community, there was no significance between this group and the clients without epilepsy for the remainder of the dependent variables. Clients with epilepsy ( $n=10$ ) had mean scores of: 0.6 for community supports; 1.2 for support from friends; 5.9 for family support; and 5.1 for paid providers. Those clients without epilepsy ( $n=35$ ) had mean scores of: 1.8 for community supports; 2.6 for support from friends; 5.3 for family support; and 4.5 for paid providers.

Some variables were found to be related to the dependent variable but were expected to be due to the nature of the variable. For example, clients who lived with their parents had more support from family. Also clients who were in the independent living skills training program had more paid supports (mean=6) than those in the pilot program (mean=0.6). This was expected due to the differences in the two programs and the time limitation placed on clients receiving services in the pilot program.

In summary, the significant relationships ( $p<.05$ ) between the independent and dependent variables found were:

1. Gender and family support: females had more support from family than

males did.

2. Gender and paid support: males had more support from paid providers than females did.

3. Living situation and paid support: clients who lived alone had more paid supports than those living with parents.

4. Epilepsy: clients without epilepsy had more community support than those with epilepsy

The differences in the samples from each program were living situation and length of time living independently. A greater percentage of the clients in the pilot program were living in the parental home. Those in the pilot program who were living independently, had done so for a much less time than those clients in the independent living skills training program.

## DISCUSSION

The analysis revealed that the researcher's hypothesis was rejected in this study. There was no correlation between developing natural supports and circles of supports and the length of independent living skills training.

On the other hand, findings indicated that gender appears to make a difference in the type of supports obtained. Females developed more supports from their family than males. Males, who depended more on paid supports to reinforce their living situation, appeared to be participating more in supported work, an indicator of community participation and possible community support. It also is a manifestation of work orientation and may indicate a sex role issue. Gender differences may be due to the way our society, in general, socializes males and females and/or the different expectations that paid trainers and family members may have for females and males. Males may have more

difficulty in asking for help from their parents or family members and may prefer to have someone from the program assist them.

A client's living situation seemed to have an effect on how much support there was from friends. In contrast to another study of clients over the age of forty (Krauss & Erickson, 1988), clients living with their parents in this sample were more likely to have support from friends than clients who were living independently. The average age of the clients in this study, however, is younger than that in the previous study. Also, this study did not compare the clients in independent living to those in community facilities. The finding, however, suggests that the family may have been an influence on their disabled family member developing some support from their own circle of friends or other connections.

This study indicated that clients who had epilepsy had less community supports than those with other diagnoses. This may be an illustration of the fear that some people in the community may have of helping a person who has seizures and/or some protectiveness on the part of family, friends, or paid supporters.

It was expected that clients in this sample, due to the nature of the training and their situation, would have higher cognitive levels and fewer behavioral problems than other Regional Center clients not living independently or receiving this type of training and in fact this was the case. Furthermore, it was expected that the higher functioning they were, the more supports they might have; this, however, was not found to be true.

The study supported Lozano's findings (1993) wherein clients who received independent living skills training maintained their independent living situation, in some cases for many, many years. This was also to be expected.



Many clients, wanting to maintain some autonomy from their parents but still needing support or not having any other supports, continued to need and receive training in order to maintain their independent living situation.

Although the hypothesis was not found to be true, the findings indicated that being female was a factor in developing support from family. Being male and living alone may be a factor in having more paid supports. The presence of epilepsy may be a factor in the development of support from community providers.

### Limitations Of The Study

There were several limitations of this study. The most important was the possible inaccuracies in the reporting of the supports from the different programs and individual instructors or specialists. Since the concept is fairly new, many of the people who completed the assessments may have different views or opinions of what is a natural support and may not know all of the people who may be available to the client for a circle of support. From this researcher's familiarity with some of the clients, there appeared to be some variability in scoring according to who was completing the assessment. Even though an attempt was made to make the assessment clear, there still may have been some confusion about how to evaluate the client and complete the assessment. This was indicated by several of the forms having two or more supports marked for a task and others only marking one (the form indicated only one be marked). Because of this, the outcome for the dependent variable may not be reliable.

Because of the pilot program's time-limited service, most of the clients receiving their training in this program would not have the option of having this

service after the six month period. Hence, unless the client had another type of service (such as a paid aide), there would be very little, if any, paid supports from this group. Because of this factor, one cannot compare the two groups for paid supports.

The sample in the study was small and did not include any clients who were not receiving independent living skills training or circle of support training. This would have provided a comparison of clients who either had training at one time in their life or who never had any training. Furthermore, there were some clients in two other programs that were not included due to a problem in locating the assessments. Including these clients could have provided additional data for this study.

#### Questions for Further Research

This study attempted to look at the factors that determine the development of circles of support. Because measurement of natural supports may be subjective and difficult, another method may be needed for this type of study. A qualitative design or component might have evidenced other factors.

The study did not look at the persons who were actually giving the training to assess their view of this concept and their methods of training. People who are not totally in agreement with the implementation of this concept could easily sabotage the client's developing natural supports. This could be looked at in further research.

There may also be other environmental factors that were not addressed in this study, such as community resources, that could effect the client's access to natural supports. This could be part of further assessments and studies.

## Conclusion

There is some evidence that the development of natural supports and circles of supports is related to gender, one's living situation, and whether or not one has the condition of epilepsy.

These findings have implications for clients choosing to live alone versus deciding to live with a parent or friend. How does a client obtain support from friends when living alone? How can parents or other facilitators help the client achieve autonomy and develop friendships? Because having support from friends is very important, these questions need to be addressed so clients will be able to develop relationships that will enhance and improve the quality of their life.

## Case Management Implications

The findings suggest that a case manager needs to be aware of gender and role expectations and the degree of healthy son/daughter-parent relationships when looking at independent living options for clients. A thorough assessment of the client's support system before the client reaches adulthood should be made so facilitation of friendships can be planned and implemented at that time if needed. As the client reaches adulthood and planning for the future is in process, the dynamics and culture of the family and social skills of the client may influence the decision for long term living arrangements. When it becomes obvious that a client may have limited choices because of these factors, the case manager may offer some insight to the client and the family about how gender and role expectations may affect these choices. The case manager can also encourage discussion on friendships and assess the client's desire in this area. A parent and client may not be aware of how living independently will affect the development of friendships. If facilitation is

needed, plans can be made to secure this service or have the parent continue involvement in this area.

As case managers want to give all clients equal opportunities for community inclusion, they need to be aware, first, of any biases or evidences of sexism in their own attitude. Are they reinforcing male clients to be more dependent on paid supports (including case managers) and discouraging the development of relationships with family and friends? Do they encourage a female client to participate in supported work or is there a need to protect her? Does the gender of the case manager make a difference?

Next, one needs to examine the way the programs and people involved with the client treat males and females. Are there different expectations according to gender? What are the gender roles from the client's family of origin? These roles may be deeply ingrained and the client may not want to look at other options, but he or she should be given the opportunity to make that choice.

For clients with epilepsy, the case manager needs to be aware that the client may be lacking community support. He or she can explore with the client any fears or unnecessary restrictions that may be a barrier to the client's participation in activities. Does the client need more information on his or her condition? Is there influence from a protective family member? Does the client have any friends? An exploration of these questions may lead to some remedies for this situation.

#### Program Planning Implications

For clients with epilepsy, especially males, there appears to be a need for intervention that will help develop more community support. A possible plan would be for instructors from the programs to coordinate or collaborate with The

Epilepsy Society for community educational opportunities. The instructor can also encourage clients with epilepsy to participate in appropriate recreational activities at community centers or churches or join special interest clubs. The instructor's ability to facilitate relationships among these clients will be critical to success.

Male clients also may benefit from a community support program which gives opportunities for male clients to interact with community providers and develop supportive relationships. Instructors can suggest possible activities and help the client arrange for them. Possible activities would be lessons in self defense, church activities, and bowling leagues. Male clients may need encouragement, education, or training in expressing their needs for support from family and friends. An assertiveness class or friendship circle may be formed for these clients.

In conclusion, this study brought up some possible factors which might affect a client's development of circles of supports and suggested some implications to case management and program planning. However, when trying to measure human relationships and supports, many factors are involved and difficulties encountered. The variables that this study addressed were only a few. A more qualitative study may further illuminate factors which influence the development of supports and address quality of life issues, the intent and essence of circles of support.

## Appendix A

### Human Subjects Review

#### Subject Recruitment

This will be a chart review of 45 case records. All subjects are clients of Inland Regional Center, a social service agency contracted with the State of California. The investigator will select 33 of 99 subjects who are all receiving independent living skills training from one program and 12 of the 28 subjects who are receiving independent living skills training from another program. All subjects have developmental disabilities and are receiving training with programs contracted with Inland Regional Center.

#### Project Description

The investigator has developed a case review form for the collection of demographic data and twelve identified variables. The measurement of natural/circles of support will be taken from an assessment form in the client case record. The study will attempt to find a relationship with the identified variables and the development of natural supports and circles of support.

#### Confidentiality of Data

The data from the case record will be identified only by the state-assigned number. No name will be taken from the case record or recorded on the review form. All review forms will be kept in the Regional Center file room or secured setting until they are destroyed.

#### Risks and Benefits

There will be no risk to any subjects. The benefit will be more information for the training programs and Regional Centers to improve the quality of life for developmentally disabled individuals.

### Informed Consent

This investigator is asking for waiver of informed consent since this is only a chart review. The investigator is an employee of the Regional Center and is allowed to review records as needed.

### Debriefing

This is not applicable.

## Appendix B

Date: \_\_\_\_\_

Client: \_\_\_\_\_

UCI#: \_\_\_\_\_

### NATURAL SUPPORT/CIRCLE OF SUPPORT ASSESSMENT

*Place a check in the column which indicates who the client would go to first if he or she would need guidance, help, or assistance with a task. If there are two or more persons who assist the client, indicate this in the comments column.*

	family member	friend/neighbor	community person	paid provider	comments
housing					
issues/problems					
household					
maintenance					
money					
management					
SSA					
issues/problems					
banking tasks					
meal					
planning/cooking					
medical					
issues/problems					
medical					
appointments					
physical					
care/assistance					
transportation					
recreation					

Is client being exploited in any way at this time? YES NO (circle one)

If yes, by whom? community person, family member, friend, neighbor, or paid provider (circle one)

Indicate how many training hours per month you are currently providing? \_\_\_\_\_

Comments/barriers to progress in developing a circle of support: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Completed by: \_\_\_\_\_



## Appendix C

### NATURAL SUPPORT/CIRCLE OF SUPPORT SURVEY

1. UCI#: \_\_\_\_\_ 2. Date \_\_\_\_\_
3. ILS Group: CIN=1 COS=2
4. Age \_\_\_\_\_
5. City \_\_\_\_\_ (small=1, medium=2, large=3)
6. Ethnicity \_\_\_\_\_ (A/A=1, Hisp.=2, Asian=3, Cau.=4, other=5)
7. Gender: M=1, F=2 8. Marital status: M=1, Si=2, D=3, Sep=4, W=5
9. Hrs./month ILST during period \_\_\_\_\_ 10. # months ILST during period \_\_\_\_\_
11. Early termination? Y N 12. # months received prior ILST \_\_\_\_\_
13. # months/years lived indep. as of 4-1-93: \_\_\_\_\_ months \_\_\_\_\_ years
14. current living situation: indep./alone=1, indep./roommate=2, w/ parent=3,  
w/other relative=4, w/ spouse=5, B/C=6, other=7 (indicate \_\_\_\_\_)
15. day program: supp. work=1, work activity=2, schl=3, ADC/AC=4, other=5, none=6

- From CDER scale                      1              2              3              4              5
16. mental retardation (#11) mild moderate severe unspecif. none
17. cerebral palsy (#17) Y N 18. autism (#23) Y N
19. epilepsy (#27a) Y N 20. other type of dev. dis. (#33a) Y N
21. mental disorder (#50a/52a) Y N
22. medical condition (#54a) Y N 23. condition impact (#54b) 0 1 2 3
24. prescribed meds for behav. (#70) 1 2 3 4 5 6
25. adjustment to change (#47) 1 2 3 4
26. social/frndsp scores: (#28) \_\_\_\_\_ 27. (#29) \_\_\_\_\_ 28. (#31) \_\_\_\_\_
29. expressive language score (#62) \_\_\_\_\_ 30. clarity (#66) \_\_\_\_\_
31. reading score (#54) \_\_\_\_\_ 32. behavior (ff) score \_\_\_\_\_

from assessment form:

#### Natural supports

33. community provider \_\_\_\_\_

34. family member \_\_\_\_\_

35. friend/neighbor \_\_\_\_\_

36. total natural supports \_\_\_\_\_

#### Other

37. paid provider \_\_\_\_\_

38. client exploited? Y N

Barriers/comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix D

<u>Paid Providers</u>	<u>Community Supports</u>
accountant	bank manager/teller
lawyer, trustee	Senior Citizen Center staff/volunteer
psychologist	minister or priest
Regional Center case manager	college counselor/peer counselor
ILS instructor	adult education instructor
medical doctors & nurses	public health department staff
occupational & physical therapists	medical supply representative
recreation therapist	community/recreation center staff
live-in aide	roommate, friend
DPSS homemaker	cleaning service staff
client's rights advocate	Legal Aid staff/public officials
speech therapist & audiologist	telephone company representative
optometrist/ophthalmologist	optician
public or private conservator	Social Security staff
day program case manager	employee's personnel director
board & care provider	apartment/property manager
nursing home staff	hair stylist/beautician
job coach	employee's supervisor
private door-to-door transportation	public bus, dial-a-ride
	moving company representative
	grocery store clerk
	plumber, electrician, etc.

## Appendix E

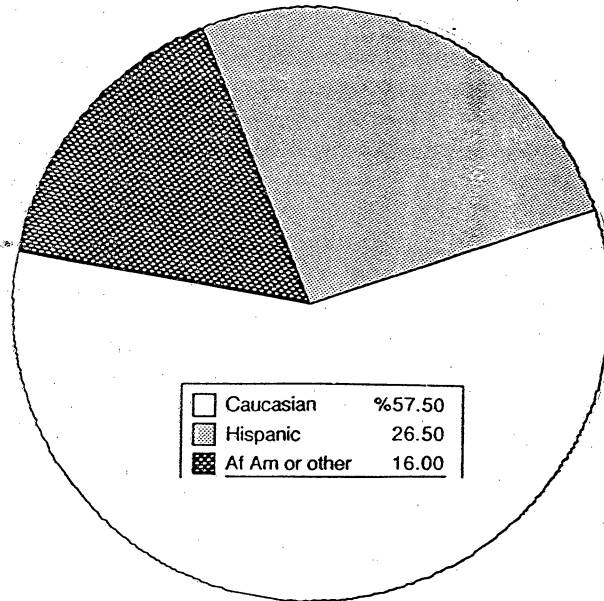


Figure 1

Ethnicity

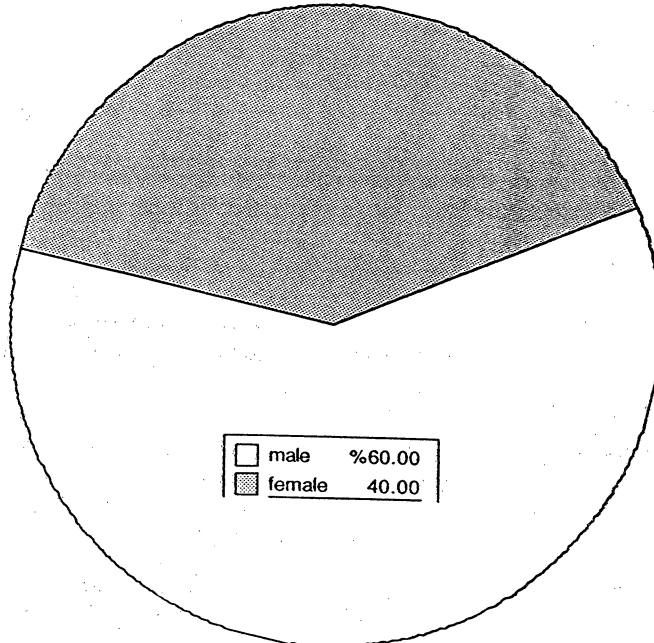


Figure 2

Gender

Appendix F

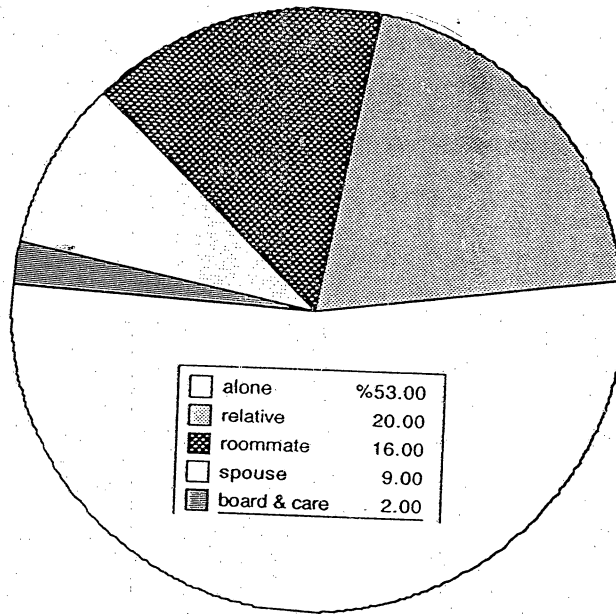


Figure 3  
Living Situation

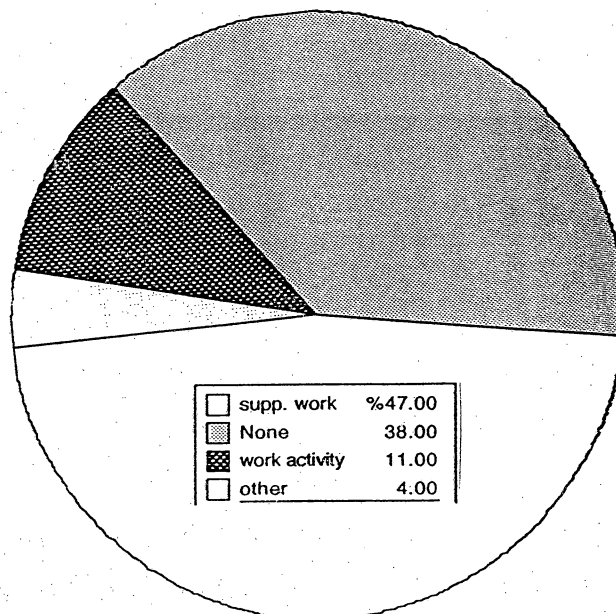


Figure 4  
Day Program

## Appendix G

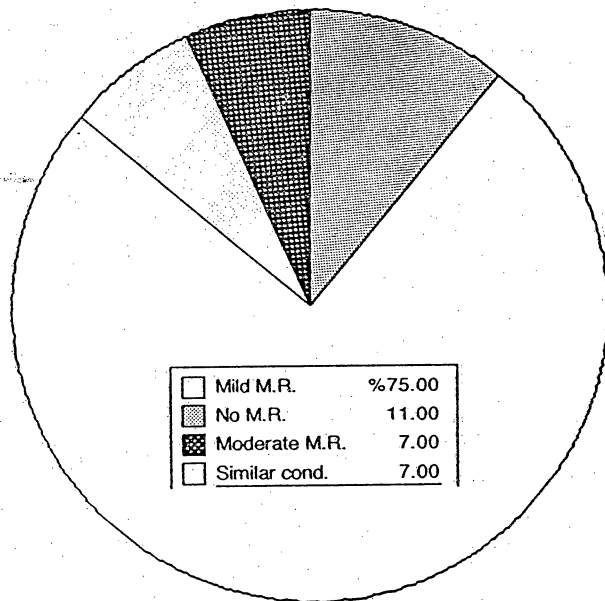


Figure 5

### Mental Retardation

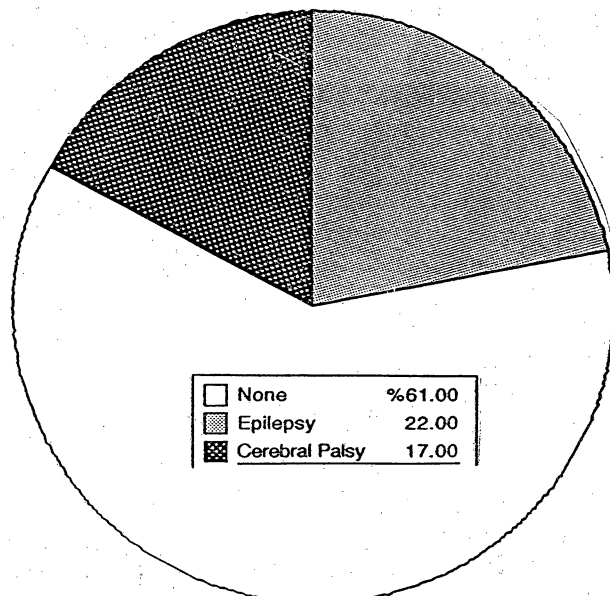


Figure 6

### Other Handicapping Conditions

## Appendix H

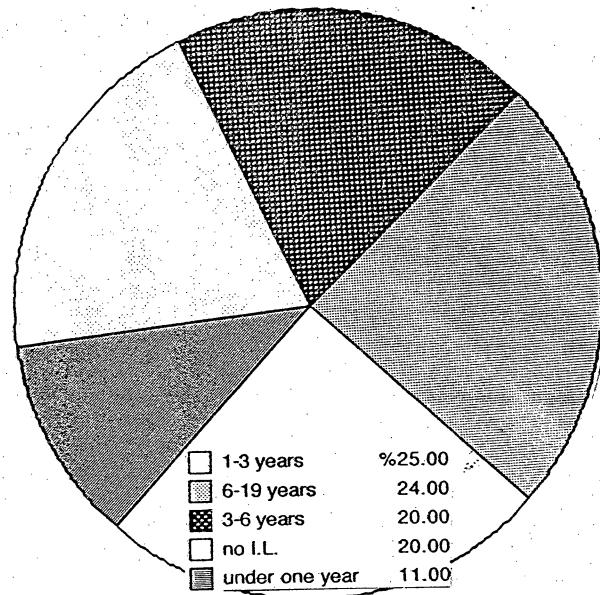


Figure 7

### Independent Living History

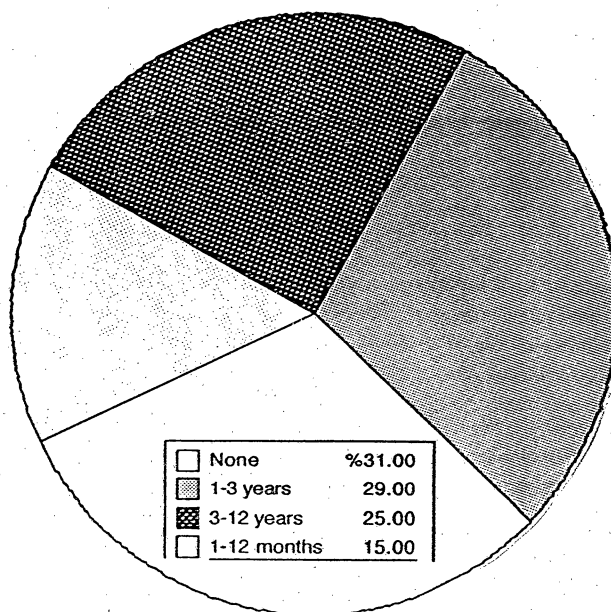


Figure 8

### Prior Training

## Appendix I

Table 1. Correlations of Total Natural Supports and Other Variables

<u>variable</u>	<u>total natural support correlation</u>
reading	$r=-.01$
language	$r=-.14$
clarity of speech	$r=-.06$
behavior	$r=-.21$
adjustment to change	$r=+.10$
social interaction	$r=-.05$
social activities	$r=+.02$
establishing friendships	$r=-.17$
independent living	$r=-.23$
prior training	$r=-.27$
age	$r=+.13$

Table 2. Correlations of Supports, Independent Living and Prior Training

<u>independent variable</u>	<u>community</u>	<u>friend</u>	<u>family</u>	<u>paid</u>
prior training	$r=+.01$	$r=+.01$	$r=-.28$	$r=+.11$
independent living	$r=+.09$	$r=+.1$	$r=-.34$	$r=-.03$

Table 3. Supports, Mental Disorder, and Mental Retardation

<u>mental disorder</u>	<u>mean community</u>	<u>mean friend</u>	<u>mean family</u>	<u>mean paid</u>
Yes ( $n=5$ )	0	1.6	4.2	7.4
No ( $n=40$ )	1.8	2.4	5.6	4.4
t-test	-0-	-.97	-.51	1.12
<u>mild mental retardation</u>				
Yes ( $n=35$ )	1.7	2.3	5.5	4.8
No ( $n=7$ )	1.4	2.9	3.6	3.9
t-test	.26	-.50	.97	.65

## REFERENCES

- Amado, Angela. (1993) "People, Not 'Services.'" AAMR News and Notes. Washington D.C.: American Assn. on Mental Retardation, 6,6.
- Amado, Angela. (1993) "Steps for Supporting Community Connections." Friendships and Community Connections Between People With and Without Developmental Disabilities. Baltimore: Paul Brookes Publishing.
- American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised. Washington, DC, American Psychiatric Association, 1987.
- Bartholomew-Lorimer, Kathy.(1993) "Community Building: Valued Roles for Supporting Connections." Friendships and Community Connections Between People With and Without Developmental Disabilities. Baltimore: Paul Brookes Publishing.
- Burke, Edward P. (1991) "Making Friends and Connections." Communitas Communicator. Manchester: Communitas, Inc., Vol. 2, No. 2.
- Castellani, Paul J. et. al (1993) "Supporting Individuals with Developmental Disabilities in the Community." A report of the Flexible Services Project. New York: N.Y. State Office of Mental Retardation and Developmental Disabilities.
- Krauss, Marty and Erickson, Marji.(1988) "Informal Support Networks Among Aging Persons with Mental Retardation: A Pilot Study." Mental Retardation. 26, 4, 197-201.
- Lozano, Beverly.(1993) "Independent Living: Relation Among Training, Skills, and Success." American Journal on Mental Retardation. 98, 2, 249-262.
- Momm, Willi and Konig, Andreas. (1989) "Community Integration for Disabled People " International Labour Review. 128, 4, 497-509.
- Mount, Beth et al (1988). What Are We Learning About Circles of Support? Communitas, Inc. Manchester, CT: Communitas, Inc.
- O'Brien, John & O'Brien, Connie Lyle. (1993) "Unlikely Alliances: Friendships and People with Developmental Disabilities." Friendships and Community Connections Between People With and Without Developmental Disabilities. Baltimore: Paul Brookes Publishing.



Reidy, Deborah. (1993) "Friendships and Community Associations."  
Friendships and Community Connections Between People With and  
Without Developmental Disabilities. Baltimore: Paul Brookes Publishing.

Rubin, Allen and Earl Babbie. (1993) Research Methods for Social Work.  
Pacific Grove: Wadsworth, Inc.

Sailor, Wayne. (1989). Integrating Individuals with Differences. Baltimore:  
Paul H. Brookes Publishing.

State of California, Senate Bill No. 1383. McCorquodale. Approved by the  
Governor 9-26-92.