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Comparison of self-determination between verbal and non-verbal residents of intermediate care facilities

Karen Anne Mahon

COMPARISON OF SELF-DETERMINATION BETWEEN VERBAL AND NON-VERBAL RESIDENTS OF INTERMEDIATE CARE FACILITIES

A Project

Presented to the

Faculty of

California State University,

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In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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ABSTRACT

This study compared verbal and nonverbal residents of Intermediate Care Facilities-Developmental Disabilities-Habilitative type (IFC-DD-H) on self-determination. The residents were compared using an adapted version of The Association for Retarded Citizen's (ARC) Self-determination scale. A choice was provided to residents on how they wanted to complete the survey. They had the opportunity to choose to learn how to use a communication device and complete the survey using the device or they can choose to complete the survey with a research assistant face to face. If it is found that residents who are nonverbal scored lower on self-determination than verbal participants objective designed to increase self-determination can be implemented through the participating agencies.

ACKNOWLEDGMENTS

I would like to thank my husband Chris, my parents and siblings for all of their support. Carol Snyder for allowing me to ask residents of rockcreek if they would like to participate in the study. Marilyn Pitts for all of her hard work as the research assistant and to devox for lending the communication device used in the study. I would also like to thank all of the professors at California State University, San Bernardino's social work department especially Dr. Janet Chang for devoting their time and effort in teaching students to become social workers. All of the professors put one hundred percent effort and more than is required.

DEDICATION

This study is dedicated to the people who live in intermediate care facilities for developmentally disabled adults in the hope that you will always continue to strive for your dreams.

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CHAPTER ONE

INTRODUCTION

Problem Statement

Do people who have intellectual disability (ID) feel they exercise their self-determination to their fullest extent? This traditionally has not been the case but in the 1960s, because of the Human Right's Movement, people with disabilities began the independent living and disability rights movement (Ward & Meyer, 1999). In the 1970s litigation like Mills vs. D.C. Board of Education and the Pennsylvania Association for Retarded Children vs. the Commonwealth of Pennsylvania led the way to new legislation protecting people who have disabilities. The Education of All Handicapped Children Act (P.L. 94-142) provided more opportunity for children who have developmental disabilities with regards to education (Ward & Meyer, 1999). In Salem, Oregon in 1973 a group called People First began to talk about equality for people who have ID in regards to housing and business enterprises (Ward & Meyer, 1999). They also created the phrase "We are people first" (Ward & Meyer, 1999). This group led to the creation of other self-advocacy groups. Today there are over 505 of these groups in existence in the U.S.

Self-advocacy groups like these have helped to make tremendous advances for people who have ID including instigating the deinstitutionalization movement of the 1970s. People who have ID have made some advances in becoming full members of our society. One of the reasons they have made these advances has to do with self-determination. Without self-determination people do not try as hard as others who do have self-determination to achieve goals (Wehmeyer, 1999).

In 1998 the Office of Special Education and Rehabilitative Services (OSERS) defined self-determination as "the attitudes and abilities, which lead individuals to define goals for themselves and to take the initiative in achieving those goals" (Ward & Meyer, 1999, p. 134). In 1989, people with various disabilities were invited by OSERS to a national conference to promote self-determination and from 1990 to 1993 OSERS supported 26 model programs working on how to teach people who have ID the skills required for self-determination (Ward & Meyer, 1999).

In the state of California, there are about 177,000 individuals who have ID and about 50,000 of those people live in community care, independent living settings, supportive living settings, skilled nursing

facilities/intermediate care facilities or developmental centers (DDS, 2003). The rest of these individuals live in their own home or with their family (DDS, 2003). Before the mid nineteen sixties, in California, there were only two options for people with ID. They could live with their family at home or they could live in a developmental center like the Frank D. Lanterman State Hospital located in Pomona, California. At that time parents who had babies with ID were told by their doctors that they would be unable to care for their child by themselves and would recommend the parents place the child in one of the developmental centers. The result of this informal policy lead to almost complete segregation for this population.

This all changed in the mid nineteen sixties when a group of concerned parents saw a need for change and put together the Lanterman Act, which addressed three main issues that effect people who have ID (DDS, 2003). The act requires the developmental centers through privately owned not-for-profit regional centers to oversee deinstitutionalization, which refers to moving people with ID from the developmental centers to small community homes, normalization of their lives from segregation and strict daily schedules to community integration and self-advocacy through sheltered and competitive employment

programs. Area boards were put into place by the state to conduct quality of life surveys to ensure that deinstitutionalization and normalization are promoting better quality of life for this population (DDS, 2003).

The idea of normalization for people who have disabilities was introduced to the world from Norway in 1946 by the Swedish State Committee for the Partially Able Bodied (Kebbon, 1997). This committee proposed that people with motor deficiencies and chronic illness be included in the ordinary system of social services and coined the phrase "normalization of like conditions" (Kebbon, 1997). At that time this was just an idea that no one thought would go anywhere. With time, this idea became the standard of service for the world. One of the reasons has to do with Denmark's lawyer and chief administrator who in 1959 developed objectives for people with ID living in his country. The main objective was to create as near normal conditions as possible for handicapped people. He stated that people who have ID should have patterns and conditions of life similar to those of the rest of the people in their community. Norway was the next country to pick up on this idea and instituted a goal for people with ID that they should lead lives as close as possible to the mainstream society (Kebbon, 1997). The idea of

normalization for people with ID quickly spread to the rest of the world including the U.S. in the 1960s (Kebbon, 1997; Robinson, 2002; Rapley & Hopgood, 1997).

Purpose of the Study

The purpose of this study was to determine the level of self determination between people with nonverbal ID and people with verbal ID living in Intermetate Care Facilities for Developmentally Disabled Adults Habilitative Type (IFC-DD-H) San Bernardino, California.

Intermediate care facilities are usually six bed group homes for people who require constant medical assistance but do not need to stay in a skilled nursing facility. The main difference between community care facilities and ICFs is that they are licensed through two different agencies.

Community care facilities are licensed through the Department of Developmental Services and are more in tune with that agencies policy than ICFs, which are licensed through the Department of Health Services. The Department of Health Services is based on a medical model whereas the Department of Developmental Services is based on an ecological model. Therefore, the Department of Health Services does not promote training in self-determination

as a treatment for people who have ID as much as the Department of Developmental Services.

Agencies that operate ICFs are still required to promote self-determination in their clients. They are concerned about this problem because one of the main objectives they have been commissioned to complete from the state is to provide community integration and normalization for their client with the goal of increasing their overall quality of life. In an ideal program, the agency helps promote normalization for their clients by assisting them in developing their own goals and objectives and then assists those clients in achieving their goals. If some of their clients are not benefiting from this process because of communication gaps, the agency's procedure for promoting normalization for those clients must be altered.

There is some speculative evidence that clients or residents who live in these types of facilities and who are nonverbal do not benefit as much from this process as people who are verbal. Smith's (2001) qualitative study of five nonverbal/inarticulate students showed that they performed at a higher level of functioning when their teachers expected them to participate fully in class (Smith, 2000). In order for these students to compete with

their verbal classmates they would have had to have some expectation that they could and would have positive outcomes. Wehmeyer(1999)found in his study of characteristics of self-determination that outcomes expectancy is one of the characteristics of people who are self-determined. Learning more about how self-determination can increase the motivation of people who have ID whether they are verbal or nonverbal will help agencies to develop policies and procedures on how to help clients develop their goals and objectives. If people who are nonverbal need extra assistance in developing self-determination then agencies have an obligation to their clients and to their funding sources to determine how to better assist them.

In order to determine if people who have ID who are nonverbal are receiving comparable training for developing their self-determination as people who are verbal looked at if there is a difference between how people who are nonverbal and verbal living in ICFs report their level of self-determination. To determine if there is a difference between people who are verbal and people who are nonverbal we asked people living in this type of facility to complete The Association for Retarded Citizen's (ARC) Self-determination Scale (SDS) and compared their results.

This showed to some extent that people who are nonverbal received the same quality of training in this area as the people who are verbal.

All of the people who live in this type of facility are very much dependent on their caregivers to meet most of their basic needs and may have felt the need to answer the questions on the survey in a positive way to sustain their level of care. This is another reason why the use of a communication device like a computer, which asked the questions and allowed for the respondent to answer was helpful in obtaining accurate answers.

Significance of the Project for Social Work

This study examined if people who have ID need more assistance in developing self-determination. The results of this study will help social workers focus their efforts in practice and policy. The results of this study showed that people who are nonverbal scored the same in self-determination as people who are verbal, social workers can to use the results of this study to help nonverbal clients create goals designed to increase self-determination. Social workers can also use the results in developing new policies on how to promote self-determination in people who have ID and are verbal.

For the most part, the results of this study can assist social workers in the assessment aspect of treatment when they are working with people who have ID. The results of this study showed that people who are nonverbal and have ID are the same level of self-determination as people who are verbal social workers can use this information during their assessment to keep an eye open for the possibility that the person they are assessing may be lacking the skills to be self-determining. They could then adjust their practice with this individual by assuming the role of teacher to teach the skills required for self-determination. At the same time, until they have those skills, the social worker can assume the role of an advocate for their client to help them to protect their rights. This study attempted to answer the question; how do verbal and nonverbal residents of intermediate care facilities score on ARC's Self-determination Scale?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter covered the theories guiding the conceptualization of self-determination and then review relevant research on self-determination as it relates to people who have ID. It will also review six main types of studies, which are related to self-determination in people who have ID. The main categories that will be covered are studies defining self-determination, comparison of staff reports and client reports of self-determination, studies on outcomes with self-determination and a model for teaching self-determination.

Theories Guiding Conceptualization

Self-determination theories stem from three different disciplines: philosophy, political science and psychology. Political science constructs of self-determination focuses on the rights of groups of people like nations to govern themselves and are linked to freedom and independence. A philosophical construct of self-determination states that there are many causes of human behavior including physiological mechanisms like hunger and psychological factors like motivation that influence behavior.

Psychological constructs of self-determination originate with the philosophical view of self-determination. Psychological theories, which address self-determination, include personality theory and motivation theory. Personality theory states that self-determination is a "determinate" of behavior (Wehmeyer, 1999, p. 60). A determinant in personality theory means an event that causes another event to occur (Wehmeyer, 1999). Also, self-determination is seen as a personality trait, which is learned and is used by individuals to cause events to occur.

Maslow's theory of motivation states that there must be wholeness to the organism; the hunger drive is not a central point of motivation and is an atypical drive. Motivation is based on basic goals, which meet ends, and not on the means to those ends. These ends are generally unconscious motivations. Needs are generally expressed simultaneously and humans are both motivated and motivating. Needs are arranged in hierarchies in which one need appears after a prior need has been satisfied. Maslow described the hierarchies of motivation for humans, as needing to fulfill basic needs first like keeping the body in a state of homeostasis. Once the body is in a state of homeostasis higher needs emerge like safety, then

motivation moves to social needs. When social needs are fulfilled self-esteem needs emerge and if all of these types of needs are met motivation turns to self-actualization. Self-actualization in this sense means to fulfill the person's greatest potential; for example musicians will create music and mother may strive to be the ideal mother (Maslow, 1943).

Motivation theory's construct of self-determination is similar to personality theory in that it defines self-determination as an internal drive and trait, which may motivate people to behave in a certain way. The definition of self-determination in ID comes from the combination of these ideas, which is: "The capacity to choose and to have those choices, rather than reinforcement contingencies, drives, or any other forces or pressures to be the determinant. It is more than a capacity, it is also a need" (Wehmeyer, 1999, p. 60).

Defining Self-determination

Wehmeyer proposed that self-determination is made up of four characteristics: autonomy, self-regulation, psychological empowerment and self-realization. To test his theory he developed a measure of self-determination composed of these four sub-sections and pilot tested the

measure to determine the scales' validity and reliability. The measure was given to special education teachers in Texas, Alabama and Virginia to administer to 251 students who have ID. Next, the measure was field tested by administering the measure to 500 students from urban, suburban and rural school districts in Texas, Virginia, Alabama, Connecticut and Colorado. Teachers who identified students as receiving special education services picked the participants for the field study. These students completed the self-determination scale and their results were compared to the results they obtained for the Norwicki-Strickland Internal-External Scale, the Intellectual Achievement Responsibility Questionnaire and the Self-Efficacy Scale. All of their scores were correlated and were found to have moderate to strong relationships between the measures. Therefore, there is some relationship between these characteristics and the self-determination scale. One of the limits to this study is that the students were not randomly picked and therefore the results cannot be generalized to the whole population. Also, these results could be biased to only represent answers of students who share similar characteristics that would also cause their teacher to pick them for the study (Wehmeyer, 1992).

Wehmeyer (1994) also thought that control may play a key role in self-determination and so he compared perceptions of control of students with and without cognitive disabilities. He compared students who have ID with students who have learning disability and students who were at risk of failure. They were asked questions on psychological empowerment, locus of control, and perception of efficacy and outcome expectancies to determine if students with ID should receive training from teachers to promote self-determination in the classroom. Two hundred and eighty two students identified by school agencies as having ID or a learning disability and students at risk of failure on the efficacy measure. Students with ID scored significantly lower on efficacy and outcome expectancy than the other two groups. This may mean the students who participated in this study with ID attribute failure internally and success externally more often than other students but the result of this study cannot be generalized because the participants were not randomly selected. One other limit to this study was that the students were given the measure in school by their teacher and may have felt that their grades would be effected by their answers (Wehmeyer, 1994).

Self-reported Self-determination

Wehmeyer and Metzler (1995) used the self-determination scale developed by Wehmeyer and associates to determine levels of self-determination of people who have ID in the United States. They distributed the SDS to members of the National Association of Developmental Disabilities Council (NADDC). Thirteen Thousand seventy three people completed the survey and 4544 of those people were identified as having ID. Results of the survey showed that people with ID perceived themselves as having fewer choices and less control of their life than people who do not have ID. One limitation of this study is that some of the respondents who have ID had significant others complete the survey. The results may have been incorrect because the surrogate respondents may have guessed incorrectly at what the actual participant would have responded (Wehmeyer & Metzler, 1995).

Wehmeyer, Kelchner, and Richards (1992) found similar results when they asked 407 people who have ID to complete ARC's SDS as well as various instruments that measure self-determined behavior they used the National Self-determination Survey which asks questions like "Did you choose where to live?" they then compared the results

and found that people who scored higher on the SDS also scored higher on the self-determination measure. The participants in this study where nominated by either ARC or People First and so one of the limitations of this study is that the results cannot be generalized to the whole population. This particular study's results may also be biased to white people because 81% of the participants were Caucasian (Wehmeyer, Kelchner, & Richards, 1996).

Comparison of Self-determination

Wehmeyer and Bolding (2000) surveyed thirty-one adults with ID, seventeen men and fourteen women. The study took place in Arkansas, California, Florida, Illinois, Maryland, Texas and Wisconsin. People who participated in the study were picked by agency staff members because of their ability to complete the measures and because they were moving from a more restrictive living or working environment to a less restrictive environment (e.g. people who were moving from institutions or nursing homes to group homes or independent community settings or moving from a day program to a sheltered workshop or from a sheltered work shop to competitive employment in the community). They were tested with two measures, ARC's SDS and the Autonomous Functioning

Checklist (AFC). Data were collected six months before and six months after the move. The results of the study showed significant differences between the scores of both measures suggesting that a more independent living or working environment leads to an increase in perceived self-determination and autonomous functioning. It cannot be determined if a move to a more independent environment causes an increase in perceived self-determination and autonomy due to the small sample size. The fact that staff pick participants means that this was not a random sample. Also, the AFC is originally meant to measure autonomy for school age children, not adults with ID and so it cannot be determined if this measure is valid and reliable for measuring autonomy for this population (Wehmeyer & Bolding, 2001).

Wehmeyer and Bolding (1999) also completed a similar study measuring self-reported levels of self-determination among adults with ID but this time there were 273 people who were recruited based on their living and working environment by agency staff and who agreed to participate in the study. The participants were measured on self-determination, autonomy and life choices. Participants were matched by characteristics, for example if they were receiving services from similar agencies, age

and gender, which was then compared with their lifestyle satisfaction. Data were collected by assistants in a face to face interview. They used ARC's SDS and AFC to measure life-style satisfaction, Results showed differences in self-determination, autonomy, satisfaction and opportunity for choice making for different settings. More specifically, the study showed significant difference between people living in group homes and sheltered workshops and people living in nursing homes/institutions and working in day programs. The results would suggest that people who have ID and live in group homes or work in sheltered workshops experience more self-determination, autonomy, life choices and lifestyle satisfaction than people who live in nursing homes or institutions. Though causality cannot be determined in this study because there was no control group, these are similar result as their first study (Wehmeyer & Bolding, 1999)

The next study reviewed having to do with a comparison of self-reported self-determination took place in Australia (Rapley & Hopgood, 1997). They looked at how community based care effected perceived independence for 34 people with ID, also comparing people who live in cities with people who live in rural settings. Behavior was measured with the Adaptive Behavior Scale (ABS)

completed by staff, which was compared to Quality of Life Questioner (QOL-Q) completed by residents. One of the main sections in this questionnaire measures subjective level of self-determination. The ABS measures independence in daily living and maladaptive or undesirable behavior in the natural environment. The researchers compared the results to determine if the measures could discriminate between individuals residing in urban settings and people residing in rural settings. The measures could not determine where the participants lived but they did show that people who were judged by administrators as low on the QOL-Q reported greater level of empowerment. In other words, increased opportunities to participate in normal activities because of fewer maladaptive behaviors meant greater subjective feelings of empowerment and life satisfaction. The results of this study cannot be generalized to the population because of the small sample size and lack of a control group and these results are only representative to the participants in this study (Rapley & Hopgood, 1997).

Wehmeyer and Palmer (1997) engaged in a study comparing levels of self-reported self-determination between students who have ID, students who have a learning disability and students who were at risk for failure in

school but were not diagnosed with a learning disability and were not taking special education classes. They compared results of 431 students in the three groups to determine if there would be a difference in locus of control between the groups. They found that the students in their study who have ID scored significantly higher on external locus of control on the Norwicki-Strickland Internal-External Scale. The authors of this study suggest that the higher level of external locus of control may be related in some way to lower level of self-determination in that it may be one f the primary characteristics required for people to develop self-determination. Some of the limitations of this study are that the students were not randomly picked which means that the results cannot be generalized to the pubic. Another limitation of this study is that they relied on student self-report with a measure that uses only yes/no answers. They cannot be sure that some of the answers are not biased positively or negatively (Wehmeyer & Palmer, 1997)

Comparison of Staff and Client Reports on Self-determination

Cummins, McCabe, Romeo, Reid, and Waters (1997) examined how accurate caregivers of people who have ID were at answering survey questions for the people they

serve. They compared data collected from 59 people who have ID and the vicarious responses of each respondent's primary caregiver, then compared the results with 69 university students as a control group. Study subjects were randomly selected from government agency lists of group homes. The scale consisted of seven main types of questions on well-being, health, productivity, intimacy, safety, community and emotional well-being. The group, comprised of people with ID, was tested three times in and eight-week period to ensure their answers were constant. The result of the study showed a weak positive relationship between the caregiver answers for health and safety with the responses from people who have ID. One of the limits of this study is the small sample sized so the results may be biased to an outlying population by chance and so the study should be replicated to increase the reliability (Cummins et al., 1997).

Stancliffe (1995) found similar results when he compared the results of questionnaires on availability of choice completed by people who have ID against caregivers asked to respond as if their client were answering. The study was administered to 47 clients of supported living agencies and 40 staff members. The questionnaire was distributed two times to each client. The first time the

questions were phrased positively for example "do you choose what to wear?" The next time the questions were phrased negatively, for example, "does someone else choose what you will wear?" the results showed a moderate to high relationship between the client responses and the staff responses except for questions on how to spend money, with whom to live and choosing job. This study suggests staff may be moderately accurate at determining client responses but the sample size was too small to generalize the results to the whole population (Stancliffe, 1995).

Rapley, Rideway, and Beyer (1997) came out with similar results as Stancliffe when they compared the results of the QOL-Q completed by clients and the results of the questionnaire filled out for the same client by the staff. The study took place in an English city and participants were nominated by network managers working in institutions and supported housing. Thirteen residents and 66 staff (two staff for every one client) were chosen to participate in the study. The results of the study suggest that staff were reasonably able to make accurate guesses for clients except when answering questions on empowerment factors (Rapley, Rideway, & Beyer, 1997). These results cannot be generalized to the whole population because the participants were not randomly selected.

Outcomes of Self-determination

Field and Hoffman (1999) looked at the importance of family involvement for promotion of self-determination in adolescents with autism and other developmental disabilities. They found that parents who developed effective skills for being a self-advocate for their children also have a significantly greater chance of passing those skills on to their children through role modeling (Field & Hoffman, 1999). The results of this study cannot be generalized to the population due to the small sample used in the study.

Wehmeyer and Schwartz (1997) conducted a study to determine the predictive value of the SDS. They recruited 80 high school seniors who have cognitive deficits, which included people who have a learning disability and people who have ID from Virginia, Connecticut, Alabama and Texas. Students were given the SDS prior to exiting school. One year after they graduated, date were collected on quality of life measures like rate of pay. The results showed a strong correlation between the participants who scored high on the SDS and higher rate of pay one year after graduation. The results provide some empirical evidence that self-determination is an important educational outcome for students with disabilities. One of the limits

of this study is the inclusion of students from different schools. The students had different school experiences, which may have effected the results (Wehmeyer & Schwartz, 1997).

Smith (2000) found similar results in a qualitative study of students with ID. She found that students who took part in the study seemed to participate less in school activities if the teacher exhibited lower expectations for them. Smith observed five nonverbal or inarticulate students attending four different high schools in the northeastern part of the U.S. She observed the students attending both special education classes and regular classes over a fifteen-month period of time. Smith found that when teachers were demanding and expected these students to perform like their classmates they did perform at higher functioning levels compared to how they functioned with teachers who had low expectations of their performance. This was a very small sample, which makes it difficult to generalize the results (Smith, 2000).

Models for Teaching Self-determination

Agran, Blanchard, and Wehmeyer (2000) developed a model for teachers to help their students set goals, take action on the goals and adjust their goals when the goal

has been reached. Nineteen students participated in the study seventeen of whom had ID. Six teachers and eight paraprofessionals collected data on the goals the students set including baseline data and data on the progress students make throughout the study. Teachers also taught the students how to set reasonable goals by teaching problem solving techniques. On average, it took the students 3.68 weeks to reach eighty percent of their targeted goal. This was higher than teacher's expectations, which were measured with the Goal Attainment Scale before the goals were made. One limit to this study is its small sample size (Agran, Blanchard, & Wehmeyer, 2000).

Summary

The majority of research in the area of self-determination and people who have ID showed that this population is less self-determined in general than the rest of the population. Motivational theory suggests that without the characteristic of self-determination people are less motivated to strive to their highest potential. Social workers working with people who have ID need to be aware of how self-determination affects the motivation of

their clients to better help them become integrated into their communities and lead more normal lives.

CHAPTER THREE

METHODS

Introduction

This study was designed to answer the question how do communication methods of residents of ICF-DD-Hs effect their level of self-determination. The parts of the study design, which will be described, include from whom the data was be obtained and why this sample was chosen, what data was collected and the instruments that were used to collect data. Next, the procedures on specifically how the study was conducted and how human rights will be protected during the study will be described. The last section will briefly cover how the data was be analyzed.

Study Design

This study used mainly a quantitative survey to explore if there is a relationship between communication styles of residents of ICF-DD-Hs and their level of self-determination. The two types of communication styles that were compared are verbal and nonverbal communication. The participant had a choice between either learning how to use a communication device to complete the survey or completed the survey in a face to face interview style with a research assistant. If the participant chose to

learn how to use the communication device to complete the survey the research assistant taught the participant how to use the communication device using mock questions on self-determination. Next, the research assistant instructed the participant to choose the button on the communication device that corresponded with the answer that they felt best describe what they believed. The research assistant let the participant know that they would be sitting far enough away so that they would not be able to hear the device. If the participant chose to complete the survey with a research assistant the research assistant taught the participant how to answer the questions using the communication device by reviewing each question and answer with the participant and showing them how to touch the screen to answer the question and move to the next question.

The survey questions were adapted from the Association for Retarded Citizen's (ARC) Self-Determination Scale (SDS)(Wehmeyer & Kelchner, 1999). The original scale uses seventy-five questions. This survey only used twenty-seven questions from this scale because this is the maximum number of questions the communication device could hold. A communication device was chosen because it will enable the participant to learn

a new method of communication if they choose this option. Also, some of the participants felt more comfortable answering the questions honestly using the communication device because they rely on staff to sustain their life in many areas and had difficulty differentiating between a research assistant and a caregiver.

Asking residents to participate by answering survey questions as opposed to using previously gathered information benefited the residents who participated in that it provided an arena for empowerment in which they were able to voice their opinion. It may also have introduced participants of the study to some of the skills required in increasing their self-determination. One of the limitations of this study is the possibility that the participant would not understand how to use the communication device. To avoid possible embarrassment for the participants who did not understand how to use the device, participants were given a choice of learning how to use the device or completing the survey in a face to face interview prior to administering the test.

Sampling

Data was obtained from residents of ICF-DD-Hs in Southern California. Selection criteria for the sample

included people who have an IQ of 70 or lower according to prior testing completed by a psychologist or psychiatrist. The sampling frame included the list of residents of ICF-DD-Hs operated by Rescare in Southern, California. A simple random sample was drawn from the list and fifty names were selected. Names were selected by assigning numbers to each name and then randomly selected numbers from a computer program designed to select numbers randomly. Verbal and written permission has been obtained from the director of the ICF-DD-Hs to ask their residents if they would like to participate in the study. A sample of fifty was chosen in anticipation that some of the randomly selected residents and/or their conservators may not consent to participate in the study and an actual sample size of thirty was collected.

Data Collection and Instruments

Data were collected using survey type questions administered by a communication device on loan from a Speech Therapist in San Diego. This device was programmed to verbally ask five demographic questions and twenty-seven questions on self-determination in both English and Spanish. After each question the device described directions on how to answer the question. If the

participant choose to complete the interview in a face to face interview, the same questions were asked by a research assistant.

The survey questions consisted of questions obtained from ARC's Self-Determination Scale (SDS). These questions were altered so that they could be answered easily using the communication device by changing some of the questions from open-ended to closed-ended type questions.

There were five sections to the survey. Section one consisted of five demographic questions that were the independent variables. The rest of the survey consists of the dependant variables, based on the four different aspects of self-determination which are autonomy, self-regulation, psychological empowerment and self-realization (Wehmeyer, 1996).

The second section measured the autonomy component of self-determination. There were six subsections of questions in this category. The first two subsections were based on independence in both routine/personal daily care and independence within the environment. The last four subsections were questions about their ability to act on the basis of their preferences, beliefs, interests and abilities in recreation, leisure time activities, community involvement, post-day program activities and

personal expression. The questions in the autonomy section were all an ordinal level of measurement (Wehmeyer, 1996) [see Appendix A].

The third section consisted of questions on self-regulation and had two subsections. The first subsection consisted of questions regarding interpersonal cognitive problem solving. This subsection asked questions with a categorical level of measurement. The next subsection in this category consisted of questions concerning goal setting and task performance and used a Lykert type scale to collect answers, which was an ordinal level of measurement (Grinnell, 2001; Wehmeyer, 1996) [see Appendix A].

The fourth section consisted of questions measuring psychological empowerment. There were no subcategories in this section and the level of measurement were nominal. The last section of the survey consisted of questions that measured self-realization. There were no subsections in this category and the level of measurement for this section was ordinal (Grinnell, 2001; Wehmeyer, 1996) [see Appendix A].

Procedures

A research assistant who was a MSW student at CSUSB who had verbally agreed to assist with the study directed each participant to go to a quite room. The research assistant than reviewed the information on the informed consent with the participant and the conservator. The research assistant then described to each participant how the communication device was operated. The research assistant then went through the entire survey and the directions for each part of the survey. If the participant indicated that they wanted to learn how to use the communication device to answer the questions the research assistant taught the participant how to use the device using mock questions and answers. Then they let the participant know that they would sit far enough away from the participant so that they could not hear or see the participants'. The research assistant then went to the furthest part of the room and engaged in other work so that they could not see or hear the participant's responses. The research assistant then sanitized the communication device with an alcohol wipe after each participant completed using the device to prevent the spread of infection.

If the resident indicated that they preferred to answer the questions in face to face interview style the research assistant read through the survey with the participant. If the participant or the conservator decide at any point during the survey that the participant should stop, the research assistant stopped the survey process. When the participant was through with the survey the research assistant reviewed the debriefing statement with the participant and the conservator.

It took approximately three hours to complete each interview using the communication device including training time and it took approximately one hour to complete each interview using the face to face interview style.

Protection of Human Subjects

Confidentiality and anonymity was ensured by not including any identifying information on the survey. The research assistant administering the survey was not given any identifying information about participants and data labeled using the randomly selected numbers assigned by the computer. Some of the residents that may be included in the sample spoke Spanish as their primary language. To ensure that the measure was culturally sensitive, the

survey was administered by the communication device in both English and Spanish as well as the face to face interview style.

Informed consent was obtained through legal conservators as well as from the participants prior to participation in the study. Many of the individuals who were included in the sample did not have a legal conservator assigned to them through the court and so informed consent was obtained through their Inland Regional Center counselor before completing the survey. If legal conservators or Inland Regional Center counselors were not present while the resident completed the survey an assigned conservator was assigned and present for the survey (see Appendix B).

The assigned conservator was already chosen and verbally agreed to participate in the study. The conservator was chosen because she has been working with people who have developmental disabilities as an Occupational Therapist for over thirty years. The conservator's role was to monitor residents while they completed the survey and to determine if the survey needed to be stopped before the resident completed the survey for any reason including emotional distress. Some of the

residents chose to use a different assigned conservator from the original assigned conservator.

A debriefing statement will be distributed to each participant and his or her conservator directly after the resident completed the questionnaire. If the questionnaire was ended before the resident completed the questionnaire, the debriefing statement was given at that time. The purpose of the debriefing statement was to desensitize the participant to the self-determination. It included the reasons for conducting the research, the way in which the participant could obtain the results of the study and contact information. The debriefing statement also described consent and some of the risks and benefits of the study as it pertains to the participant. A current referral list was be included on the debriefing statement in case participants suffered from emotional distress as a result of participating in this study and wished to seek therapeutic support (see Appendix C).

Some of the benefits that could have resulted from participating in the study may have been that the resident gained the ability to express their concerns about self-determination in a public manor. They could have learned a new method of communicating. They may have learned what some of the components of self-determination

are and how to increase their own self-determination. Some of the risks of participating in this study included on the informed consent and debriefing statement included the risk of emotional discomfort due to the realization that they did not have as much self-determination as they thought they did before participating in this study (see Appendix C).

Data Analysis

The data obtained from this study was analyzed using descriptive and inferential statistics. Statistical analysis was used to determine if an association exists between the independent variables and the dependent variables.

The univariate tests that were employed to evaluate the data included the mean, mode, the standard deviation and frequency distribution. The bivariate tests that were used to analyze the data and determine the significance of associations were T-test and a chi-square. T-tests were performed to determine if there was a significant different between levels of self-determination between residents of ICF-DD-Hs who are verbal as compared to residents who are nonverbal (Grinnell, 2001).

Summary

The design of the study was mainly a quantitative categorical survey, which was administered by a research assistant who gave the participants the opportunity to learn how to use a communication device to complete the survey or the opportunity to complete the survey using a face to face interview. The research assistant did not know any of the participants identifying information to ensure confidentiality and anonymity. The sample that was used in this study was drawn from residents of ICF-DD-Hs in Rescare facilities located in Southern California. Questions for the survey were gathered from ARC's SDS. The survey was administered to residents instead of gathering information from previously collected data in order to obtain residents' opinion of self-determination. After the data was obtained it was analyzed using both univariate and bivariate statistics.

CHAPTER FOUR

RESULTS

Introduction

This section presents findings from the questionnaire which was designed to determine if there were any difference in self determination between verbal and nonverbal residents living in ICF-DD-H facilities in the Inland Empire.

Presentation of the Findings

Demographic Characteristics of the Respondents'

Table 1 shows the demographic characteristics of the respondents. There are a total of thirty participants in the study. The age range of the respondents is 25 to 75 years and the mean age of the respondents is 47.7 years. Fifty percent of the respondents were between the ages of 40-49.

The gender of the respondents in the sample is 60% male and 40% female. The verbal status of the respondents in the sample was 50% verbal and 50% non-verbal.

Table 1. Demographic Characteristics of the Respondents'

Variable N = 30	Frequency (n)	Percentage (%)
Age		
20-29	1	3.3%
30-39	3	9.9%
40-49	15	50%
50-59	7	23.2%
60-69	3	10%
70-79	1	3.3%
Gender		
Male	18	60%
Female	12	40%
Verbal Status		
Verbal	15	50%
Non-verbal	15	50%
Data Collection Method		
Communication device	13	43.3%
Interview	17	56.7%

Respondents had the choice of completing the questionnaire using a communication device or by having a research assistant assist the respondents to complete the measure. Thirteen respondents (43.3%) chose to use the communication device to complete the questionnaire and seventeen the respondents (56.7%) chose to complete the questionnaire with the research assistant.

Characteristics of Respondents' Responses to Autonomy Variables

Table 2 shows the frequency distribution of the respondents' autonomy items. In regards to the statement, "I make my own meals and snacks" 22 respondents (73.3%) reported "every time I have the chance" while eight

respondents (26.7%) responded "not even if I have the chance." Another statement, "I keep good personal care and grooming", 25 respondents (83.3%) indicating "every time I have the chance" compared to 5 respondents (16.7%) responded "not even if I have the chance." In regards to the statement, "I make friends with other people my age", 21 respondents (70%) responded "every time I have the chance" and nine respondents (30%) answered "not even if I have the chance." In regards to the statement, "I deal with sales people at stores and restaurants", 18 respondents (60%) indicating "every time I have the chance" compared with 12 participants (40%) reported, "not even if I have the chance." In regards to the statement, "I participate in free time activities based on my interests", 21 respondents (70%) responded "every time I have the chance" compared to nine respondents (30%) responded "not even if I have the chance."

In regards to the statement, "I listen to music that I like", 21 respondents (70%) responded "every time I have the chance" while nine participants (30%) of the sample respond "not even if I have the chance." In regards to the statement, "I volunteer for things that I am interested in", 18 participants (60%) responded "every time I have the chance compared with 12 participants (40%) responded

Table 2. Frequency Distribution of the Autonomy Variables

Variable N = 30	Frequency (n)	Percentage (%)
I make my own meals and snacks		
Not even if I have the chance	8	26.7%
Every time I have the chance	22	73.3%
I keep good personal care and grooming		
Not even if I have the chance	5	16.7%
Every time I have the chance	25	83.3%
I make friends with other people my age		
Not even if I have the chance	9	30%
Every time I have the chance	21	70%
I deal with sales people at stores and restaurants		
Not even if I have the chance	12	40%
Every time I have the chance	18	60%
I participate in free time activities based on my interests		
Not even if I have the chance	9	30%
Every time I have the chance	21	70%
I listen to music that I like		
Not even if I have the chance	9	30%
Every time I have the chance	21	70%
I volunteer for things that I am interested in		
Not even if I have the chance	12	40%
Every time I have the chance	18	60%
I take part in community groups like church or hobbies		
Not even if I have the chance	14	46.7%
Every time I have the chance	16	53.3%
I do day program and free time activities based on my career interests		
Not even if I have the chance	10	33.3%
Every time I have the chance	20	66.7%
I choose my clothes and the personal items I use every day		
Not even if I have the chance	6	20%
Every time I have the chance	24	80%
I choose how to spend my personal money		
Not even if I have the chance	13	43.3%
Every time I have the chance	17	56.7%

"not even if I have the chance." In regards to the statement, "I take part in community groups like church or hobbies", 16 participants (53.3%) responded "every time I have the chance" while 14 people in the sample (46.7%) responded "not even if I have the chance." In regards to the statement, "I do day program and free time activities based on my career interests", with 20 respondents (66.7%) indicating "every time I have the chance" compared 10 respondents (33.3%) reported "not even if I have the chance."

In regards to the statement, "I choose my clothes and the personal items I use every day", 24 of the participants (80%) reported "every time I have the chance" while 6 respondents (20%) reported "not even if I have the chance." In regards to the statement, "I choose how to spend my personal money", 17 respondents (56.7%) reporting "every time I have the chance" compared with13 respondents (43.3%) responded "not even if I have the chance." A common characteristic between the way all of the respondents answered the autonomy section questions is that the majority of the respondents answered "every time I have the chance" for all of the questions more often than using the "not even if I have the chance" answer.

Characteristics of Respondents' Responses to Self-Regulation Variables

Table 3 shows the frequency distribution of the self-regulation items respondents were given a hypothetical scenario for them to choose from the two options, a more self-regulating action and a less self-regulation action. There are two scenarios in this section. In the first scenario, the respondent was told; "you are sitting in a planning meeting, you want to take a class where you can learn to work as a cashier in a store. The other members or your team want you to take a Family and ChildCare class. You can only take one of the classes." Seventeen (70.8%) choose the more self-regulating response "I would tell the team what I want," while 7 respondents (39.2%) choose the less self regulating response "I would ask the team for what I want."

The second scenario is a day program story in which the respondent was told; "you are at a new day program and you don't know anyone. You want to have friends," Fifteen respondents (65.2%) chose the less self-regulating response and 8 respondents (34.8%) chose the more self-regulating response "I would introduce myself to members." It seems that the majority of respondents

sampled in this study were capable of self-regulating during multidisciplinary team meetings but when it came time to work with peers in a less structured environment it appears more individuals have a difficulty self-regulating.

Table 3. Frequency Distribution of Self-Regulation Variables

Variable N = 30	Frequency (n)	Percentage (%)
Cashier Story		
I would tell the team what I want	17	70.8%
I would ask the team for what I want	7	39.2%
Day Program Story		
I would ask to be introduced by staff	15	65.2%
I would introduce myself to members	8	34.8%

Characteristics of Respondents' Response to Goal Setting and Task Performance Variables

Table 4 shows the frequency distribution of goal setting and task performance items. The items in this section were altered from ARC's standardized self-determination measure to fit into the device.

In regards to the statement, "I have a clear plan for the future", 17 respondents (60%) responded affirmative while 11 participants (39.7%) of the sample responded negative. The result of the other variable in this section was almost opposite to the last variable. The second

Table 4. Frequency Distribution of Goal Setting Variables

Variable N = 30	Frequency (n)	Percentage (%)
I have a clear plan for the future		
Yes	17	60.7%
No	11	39.3%
I am not sure what the future holds for me		
Yes	16	55.2%
No	13	44.8%

variable in this section, "I am not sure what the future holds for me" 16 respondents indicated "yes" (55.2%) and 13 respondents or 44.8% of the sample responded "no," which was considered more goal setting and task performance ability. There were only two variables in this section and the variables may have need to be worded differently because they could have sounded like the same question to the respondents'.

Characteristics of Respondents' Responses of Psychological Empowerment Variables

Table 5 shows the empowerment variables located in the fifth section of the questionnaire. The respondents were asked to choose between a more psychologically empowered response and a less psychologically empowered response. The first variable, 14 participants (50%) responded " I tell my friends what I want to do" and 14 respondent (50%) responded " I do what my friends what". The next variable in this section, 21 participants (75%)

Table 5. Frequency Distribution of Psychological Empowerment Variables

Variable N = 30	Frequency (n)	Percentage (%)
Friends		
I do what my friends want	14	50%
I tell my friends what I want to do	14	50%
Feelings		
I tell others when they hurt my feelings	21	75%
I am afraid to tell people when they hurt my feelings	7	25%
Trying		
It is no use to keep trying because that won't change things	15	53.6%
I keep trying even after I get something wrong	12	42.9%
Work		
I am able to work with others	18	64.3%
I can not work well with others	10	35.7%
Choices		
My choices are not honored	15	53.6%
I make choices that are important to me	13	46.4%

responded "I tell others when they hurt my feeling" and 7 respondents (25%) responded " I am afraid to tell people when they hurt my feelings." Fifteen respondents (53.6%) reported "it is no use to keep trying because that won't change things" while 12 participants (42.9%) reported "I keep trying even after I get something wrong." Eighteen participants (64.3%) reported "I am able to work with others" compared with 10 participants (35.7%) indicated "I can not work well with others." Fifteen respondents

(53.6%) reported "My choices are not honored" while 13 participants (46.4%) reported they " make choices that are important to me."

There is almost equal distribution of participants who responded to more psychologically empowered choices and less psychologically empowered choices. A slightly higher number of participants who chose the more psychologically empowered responses.

Characteristics of Respondents' Responses to Self-Realization Variables

Table 6 shows the frequency distribution of self-realization items. This section of the measure is also a nominal level of measurement. Due to the lack of memory in the communication device items were altered from the original Lykert type scale in ARC's self-determination scale to fit the device.

In this section, respondents were given a statement to respond "yes" or "no." In regards to the statement, "I do not feel ashamed of any of my emotions", 16 participants (57.1%) reported an affirmative "yes" while 12 participants (42.9%) responded "no." In regards to the statement, "I can like a person even if I don't agree with them, " 17 respondents (60.7%) reported "yes" compared with 11 participants (39.3%) reporting "no." Twenty-one

Table 6. Characteristics of Respondents' Responses of Self-Realization Variables

Variable N = 30	Frequency (n)	Percentage (%)
I do not feel ashamed of any of my emotions		
Yes	16	57.1%
No	12	42.9%
I can like a person even if I don't agree with him/her		
Yes	17	60.7%
No	11	39.3%
I don't accept my own limitations		
Yes	17	60.7%
No	11	39.3%
I like myself		
Yes	21	84.0%
No	4	16.0%
I am not an important person		
Yes	14	51.9%
No	13	48.1%
I am confident in my abilities		
Yes	18	69.2%
No	8	30.8%

respondents chose "yes" to "I like myself" and 4 participants chose "no," the less self-realizing response. In regards to the statement, "I am confident in my abilities," 18 respondents (69.2%) indicated "yes" while 8 respondents (30.3%) reported "no."

All of the variables included in this study in this section, were responded to in a more self-realizing manner, by the majority of the respondents in the study. This may mean that the people who participated in this

study feel comfortable with the self-realization aspect of their self-determination. They have a good understanding of who they are.

Independent Sample t-Test Results

T-test disclosed that there were no significant differences between verbal residents and nonverbal residents of ICF-DD-Hs in their self-determination ($t(14) = .513$, $p = .616$). But, nonverbal residents scored slightly higher in self-determination. There were also no significant differences between men and women who live in ICF-DD-Hs in self-determination ($t(14) = .983$, $p = .342$), but female residents had slightly higher level of self-determination then men. T-test results revealed that residents who chose to use the communication device instead of interview had scored slightly higher in overall self-determination but the t test revealed that there were no significant difference between the groups in self-determination, ($t(14) = .983$, $p = .342$).

The t test approached a significant difference between verbal and nonverbal residents who chose the interview as opposed to the communication on the autonomy section of the self-determination questionnaire ($t(28) = 2.025$, $p = .052$). This is an unexpected finding since it would seem that residents who are more autonomous

would want to complete the questionnaire independently using the communication device. Maybe the less autonomous residents chose the communication device more often because they had the desire to become more autonomous.

Verbal ICF-DD-H residents scored slightly higher in the autonomy portion of the self-determination questionnaire. The t test revealed no significant difference between the two groups in autonomy ($t(28) = -.749$, $p = .460$). Females who live in ICF-DD-Hs scored slightly higher on autonomy than male residents. However, the t test showed no significant gender difference on the autonomy section of the self-determination scale ($t(28) = -1.800$, $p = .083$).

T-test revealed that nonverbal ICF-DD-H residents had significantly more self-regulation than verbal ICF-DD-H residents, ($t(19) = -3.484$, $p = .002$). It may be that nonverbal residents acquire this characteristic at a significantly greater rate over verbal ICF-DD-H residents because they need to be more patient when communicating their needs to caregivers or others because it may take longer to communicate their needs and for others to understand what they are trying to communicate.

Residents who chose to participate in the study using the interview scored slightly higher in self-regulation

than those who chose to use the communication device. However, the t test showed no significant difference between the participants in self-regulation, ($t(19) = -.390$, $p = .701$).

Men score slightly higher in the self-regulation portion of the self-determination scale. The t test revealed that there was no significant gender difference who live in ICF-DD-Hs on self-regulation, ($t(19) = 1.027$, $p = .317$).

The t test showed that there were no significant differences between verbal residents and nonverbal residents on the goal setting section of self-determination, ($t(19) = -3.484$, $p = .183$). Verbal residents had slightly higher scores on the goal setting section of the self-determination scale than nonverbal residents. The t test showed that there were no significant differences between residents who chose to use the communication device and residents who chose the interview on goals setting, ($t(26) = .310$, $p = .759$).

Men scored slightly higher on the goal setting section of the self-determination scale than women and the t test revealed that there were no significant gender differences in goal setting ($t(25) = .215$, $p = .831$).

Nonverbal residents of ICF-DD-Hs scored slightly higher than verbal residents in the psychological empowerment section of the self-determination scale. The t test showed no significant difference between verbal and nonverbal residents in psychological empowerment ($t(25) = -1.744$, $p = .093$). Residents who chose to use the communication device scored slightly higher than those who chose the interview style in the psychological empowerment portion of the questionnaire. The t test revealed no significant differences between the two groups on psychological empowerment ($t(25) = 1.762$, $p = .077$).

Also, men scored slightly higher than women did in the psychological empowerment section of the self-determination scale. The t test revealed that there were no significant gender differences in psychological empowerment ($t(25) = 1.844$, $p = .077$).

The last section of the questionnaire was on self-realization. Residents who are nonverbal scored slightly higher on the self-realization portion of the self-determination scale than verbal residents. However, the t test showed no significant differences between verbal and nonverbal residents in self-realization ($t(24) = -1.424$, $p = .169$).

Residents who chose the communication device had slightly higher scores in self-realization than those who chose the interview. However, the t test showed that there were no significant differences between these groups in self-realization ($t(24) = 1.424$, $p = .169$). Women in this study had slightly higher scores in self-realization than men. The t-test showed that there were no significant gender differences in self-realization ($t(21) = -.352$, $p = .728$).

Summary

There were no overall significant differences between the independent variables in total self-determination, autonomy, goal setting and task performance, psychological empowerment or self-realization between the verbal and nonverbal residents. Nonverbal residents had significantly more self regulation than verbal residents but gender and data collection method did not make a significant difference in self regulation for this group.

CHAPTER FIVE

DISCUSSION

Introduction

In this chapter the researcher will examine and discuss the study's significant finding and implications. Also, the researcher will identify the study's limitations, review its implications for the field of social work practice and identify possible further research in self-determination with residents of ICF-DD-Hs.

Discussion

Verbal ICF-DD-H residents seem to receive more attention than nonverbal residents because verbal residents are able to communicate in a manor that provides both members positive rewards from the reciprocal verbal interaction. Nonverbal ICF-DD-H residents cannot provide the same kind of communication feedback or positive reward. Some nonverbal ICF-DD-H residents can only offer body language through hand gestures or facial expressions and/or sign language to provide some kind of feedback during a conversation, while other nonverbal residents may not be able to provide even meaningful facial expressions.

There were thirty people over the age of eighteen and under the age of seventy-five who participated in this study. Exactly fifty percent of the study's population was verbal and fifty percent was nonverbal. There was almost an equal gender distribution and an equally distribution of participants chose to complete the questionnaire with a research assistant as opposed to those who completed the questionnaire with self-learned communication device. Interestingly, there were no significant difference between participants who chose to complete the questionnaire using the communication device as opposed to respondents who completed the questionnaire with the research assistant in an interview in their level of self-determination.

Self-determination was broken down into its five component characteristics: autonomy, self-regulation, goal setting, and psychological empowerment. There were only slight differences between the percentages of the participants in all of the components.

In terms of responses of the five components, slightly more respondents chose the more self-determining items more often in the autonomy section. The majority of the respondents' selected the more self-determining response in the self-regulation section. In last three

components of the questionnaire, psychological empowerment; goal setting and self-realization there was almost an equal frequency distribution of items among both verbal and nonverbal resident. Almost half responded they had a high level of self-determination and the other half responded they had a low level of self-determination.

A series of t-tests were used to compare the five components and the tests showed no significant differences between verbal and nonverbal residents living in ICF-DD-Hs in self-determination. This means that the hypothesis was not supported. However, there was one unexpected significant finding which was that the nonverbal residents had significantly greater self-regulation than verbal residents.

This may be due to nonverbal residents need to be patient when communicating needs with caregivers. For instance, it may take much greater effort for a nonverbal resident living in an ICF-DD-H to request a particular snack because it could take several attempts than it would take for a verbal resident to request a snack.

Also, the t-test assessing the difference between verbal and nonverbal residents who chose the interview as opposed to the communication device on the autonomy section of the self-determination questionnaire approached

a significant difference. This showed that verbal residents of ICF-DD-Hs were almost more likely to ask to complete the questionnaire with the help of the assistant instead of completing the questionnaire independently using the communication device. This is an unexpected finding since it would be expected that residents who are more autonomous would want to complete the questionnaire independently using the communication device. Maybe the less autonomous residents chose the communication device more often because they had the desire to become more autonomous.

The results found in this study were quite different from the results found in another study (Wehmeyer, 1994) which tested participants affiliated with ARC and People First. This study adopted an operational definition of self-determination to include the component parts located in the questionnaire used in this study.

The results of Wehmeyer's study are different from the results of this study in that there was only one significant finding in the current study. Wehmeyer's study found significant findings for all of the component parts of self-determination. The possible reasons for the difference in the findings include the fact that in the current study utilized a very small convenience sample. If

a larger sample size were used in the current study there may have been similar results to the example. Also, the population used in the current study was not representative of the general ID population and so if the current study had used a more representative ID population the current results may have been similar to the example.

Limitations

One limitation of this study includes the small sample size that may be part of the reason for the different results from the above-mentioned study. The small sample size also makes it difficult to generalize the results. Perhaps a larger sample would have yielded different results.

A second limitation of this study was some of the questions used in the questionnaire may have been confusing to the participants. The obviously confusing questions were not included in the t tests but there may have been other questions that were confusing that were not dropped that could have been. The substantial adaptation of the scale most likely contributed to the difference in significant findings from Wehmeyer's study as well.

A third limitation to the study may have been the possibility that the population of the study was not representative of the general ID population. If the sample were more representative of the general ID population, the results may have been different.

Recommendations for Social Work Practice, Policy and Research

The implications for social work practice are encouraging despite the mentioned limitations. This study's findings revealed that both verbal and nonverbal residents of ICF-DD-Hs have similar levels of self-determination. This information can be used in social work practice to determine through further research which parts of ICF-DD-Hs program are fostering equality in self-determination and implement it through program and policy.

Social work practice recommendations include notifying and educating ICF-DD-Hs about the result of this study and other similar study's on self-determination. Agencies could use the information that nonverbal residents scored significantly higher on self-regulation than verbal residents in ICF-DD-Hs to utilize the strengths based perspective and accentuate potential self-regulation in nonverbal residents. Staff members

could also be educated on self-determination specifically on what the components are and how to promote self-determination within the facilities they work.

Social work policy recommendations include incorporating self-determination wording into California Code of Regulations Title 17. Even though this study show that there was equal distribution of self determination between verbal and nonverbal residents of ICF-DD-Hs there was some slight evidence from the frequencies that residents did not score very high on self determination overall. One way to make the system more effective in promoting independence which is key wording in Title 17, is to promote self-determination. The way to accomplish this task may be to alter Title 17 to include self-determination.

A recommendation for social work research is to conduct a follow-up study on the unexpected significant finding that nonverbal residents have more self regulation than verbal residents. It would be interesting to determine if this is due to their need to be patient with communication with caregivers. If so, social work policy and practice may be effected by having to alter programs to meet the special needs of nonverbal clients. Future research could also include determining precisely just how

much self-determination ICF-DD-H residents currently score at using ARC's self-determination Scale.

Conclusion

The overall findings from this research study suggest that nonverbal residents of ICF-DD-Hs as well as verbal residents of ICF-DD-Hs share relatively the same level of self-determination. This may mean that the ICF-DD-H program is working to promote self-determination equally for both verbal and nonverbal residents. The one unexpected significant finding showed that nonverbal residents scored significantly higher than verbal residents did in self-regulation. Further research would determine if this is due to their need to have greater patient with caretaker than verbal resents when trying to communicate that their needs be met.

APPENDIX A

QUESTIONNAIRE

Adapted ARC Self-Determination Scale

Please check one:

Study participant is verbal _____ Study participant is non-verbal _____

Used the communication device _____ Interview _____

Age _____ Gender _____

Section I: Autonomy

Circle the answer on each question that BEST tells how you act in that situation. There are no right or wrong answers. Check only one answer for each question. (If your disability limits you from actually performing the activity, but you have control over the activity (such as a personal care attendant), answer like you performed the activity.)

1. Not even if I have the chance
2. Every time I have the chance.

1A Independence: Routine personal care and family oriented functions.

I make my own meals or snacks

1 2

I keep good personal care and grooming

1 2

1B Independence: Interaction with the environment

I make friends with other people my age

1 2

I deal with sales people at stores and restaurants

1 2

1C Acting on the basis of preferences, beliefs, interests and abilities: Recreational and Leisure time

I participate in free time activities based on my interests

1 2

I listen to music that I like

1 2

1D Acting on the basis of preferences, beliefs, interests and abilities: Community involvement and interaction

I volunteer in things that I am interested in

1 2

I take part in community groups like church groups or hobbies

1 2

1E Acting on the basis of preferences, beliefs, interests and abilities: post-day program

I do day program and free time activities based on my career interests.

1 2

1F Acting on the basis of preferences, beliefs, interests and abilities: Personal expression.

I choose my clothes and the personal items I use every day.

1 2

I choose how to spend my personal money

1 2

Section II: Self-Regulation

2A Interpersonal cognitive problem-solving

Each of the following questions tells the beginning of a story and how the story ends. Your job is to tell what happened in the middle of the story, to connect the beginning and the end. Review the beginning and the ending for each question. Then choose the best answer for the middle of the story. There are no right or wrong answers. Remember, choose the one answer that you think BEST completes the story.

Beginning: You are sitting in a planning meeting (ISP) You want to take a class where you can learn to work as a cashier in a store. The other members of your team want you to take a Family and Child Care Class. You can only take one of the classes.

Ending: The story ends with you taking a vocational class where you will learn to be a cashier.

Pick one middle story of how you would get to the same ending.

I would tell the team what I want

Or

I would ask the team for what I want

Beginning: You are at a new day program and you don't know anyone. You want to have friends.

Ending: The story ends with you having many friends a the new day program

Pick one middle story of how you would get to the same ending.

I would ask to be introduce by staff

Or

I would introduce myself to members

2B Goal setting and task performance

Directions: The next section asks about your plans for the future. Again, there are no right or wrong answers. For each question answer if you strongly agree, agree, disagree or strongly disagree with the statement.

I have a clear plan for what I want in the future.

yes no

1 2

I am not sure what the future holds for me.

yes no

1 2

Section III: Psychological Empowerment

Directions: Check the answer that BEST describes you.

Choose only one answer for each question. There are no right or wrong answers

- ❑ I usually do what my friends want…or
- ❑ I tell my friends if they are doing something I don't want to do.

- ❑ I tell people when they have hurt my feelings… or
- ❑ I am afraid to tell people when they have hurt my feelings.

- ❑ It is no use to keep trying because that won't change things… or
- ❑ I keep trying even after I get something wrong.

- ❑ I am able to work with others… or
- ❑ I cannot work will with others.

- ❑ My choices are not honored…or
- ❑ I make choices that are important to me

Section IV: Self- Realization

Directions: Tell whether you think each of these statements describe how you feel about yourself or not. There are no right or wrong answers. Choose only the answer that BEST fits you.

I do not feel ashamed of any of my emotions

yes no

1 2

I can like people even if I don't agree with them

yes no

1 2

I don't accept my own limitations

yes no

1 2

I like myself

yes no

1 2

I am not an important person

yes no

1 2

I am confident in my abilities

yes no

1 2

APPENDIX B

INFORMED CONSENT

Informed Consent
(Resident)

My name is Karen Mahon and I am a student in the Masters of Social Work Department at California State University, San Bernardino. I am working on a school project on how people make choices who live in homes like the home you live in. I am looking to see if people who cannot talk make choices about their life the same way people who can talk make choices about their life. I also want to see if people who talk and people who don't talk do the things they decide to do the same way. If you don't want to answer questions like this it is ok. No one will be mad and nothing bad will happen. You will not get in trouble in anyway. If you do want to answer questions about how you make choices you do not have to worry about anyone knowing what your answers are because I will make sure no one will see them. If someone sees the answers by accident they will not know the answers are your answers because I will not put your name on the paper with your answers.

A couple of good things can happen if you feel like answering questions about how you make choices like you could learn a new way to talk to people if you want to learn how to use a machine to help you answer the questions. Also, you could learn a little bit about how to make decisions differently and learn how to do the things you choice to differently just by hearing the questions and answering them. If you decide that you want to answer questions about how you make choices and you start answering the questions and in the middle of answering the questions you decide that you don't want to answer anymore questions you can stop and no one will be mad and you will not get in any trouble. Also, after you are done answering the questions you can tell your facility manager to call me if you don't want me to give your answers to my teacher and I will through them away. I will not be mad if you don't want to have the teacher see your answers. I like it when people tell me what they want. Also, the questions I will ask are not like test questions because there are no right or wrong answers. The best answers are just answering the question the way you want to. One bad thing that can happen when you answer the questions is that you might feel sad. If you start to feel sad please tell me so I can stop asking you questions. It is very important to me that you don't feel sad. If you start to feel sad from answering the questions after I have left please tell your facility manager so they can call me or Marian Kalman the Behavioral Specialist to talk to about feeling sad. You don't have to call us if you start to feel sad you can talk to anyone you want to but please talk to someone because feeling sad isn't fun and talking to someone can help you feel better. If you want to learn how to use the machine to answer the questions it will take about two hours to learn how to use the machine and one hours to answer the questions. If you want the answer the questions with someone instead of using the machine it will take about an

hour. One hour is about the same amount of time it takes for everyone to eat dinner. If you get tired and want to stop it is ok. If you want help while you are answering questions it is also ok.

When I am done talking to everyone who wants to talk to me about how they make their choices I an going to give the answers without any names just the answers to my teacher and to the people who work at your house. The teacher at my school said that I can ask you my questions but only if you say I can. If you want to answer the questions sign your name on the line. If you don't want to sign your name but you want to answer the questions it is ok. I can help you sign your name if you want me to or you can have someone else help you. If you don't feel like answering question don't worry. No one will be mad and you will not get in trouble. It was fun for me to talk to you and get to know you anyway.

Resident Signature _____ Date _____

Witness Signature _____ Date _____

INFORMED CONSENT

My name is Karen Mahon and I am a student in the Masters of Social Work Department at California State University, San Bernardino. I am conducting a study regarding self-determination and developmental disability. Participation in this study is completely voluntary and should your family member or the person you are conservator for choose to participate, you will remain completely anonymous, as no identifying information will be obtained.

The benefits of participating in this study may include learning how to use a new method of communicating if your family member or the person you are a conservator for choose to learn how to use the communication device and learning how to be more self-determining. Participation in this study may cause psychological discomfort from answering questions on self-determination.

The results of this study will be presented as a final research project for the Masters of Social Work program at California State University San Bernardino. The result will be available at the university in the Pfau Library and the main office of the agency running your program after June 2004.

The CSUSB Institutional Review Board has approved this project. Dr. Chang who is supervising this research project may be reached at the California State University, San Bernardino, Department of Social Work 909-880-5184.

This survey will take approximately three hour to complete if your family member or the person you are a conservator for choose to be trained to use a communication device and will take approximately one hour if your family member or the person you are a conservator for choose to participate in the study by completing a face to face interview with a research assistant. Your family member or the person you are a conservator for may choose to stop participating in this study at anytime up until May 2004 even while you are answering the questions. Thank you for your participation in this study.

Conservator Signature _____ Date _____

Family Member Signature _____ Date _____

Counselor Signature _____ Date _____

APPENDIX C

DEBRIEFING STATEMENT

Debriefing Statement
(Resident)

Thank you for helping me with my school project. You have helped me to find out if people who cannot talk make choices and decisions the same way people who do talk make choices and decisions. My name is Karen Mahon and my teacher's name is Dr. Chang. If you want to talk to someone about the questions you answered you can call Dr. Chang at (909) 880-5184. You can also ask someone like one of the people who work in your home to call Dr. Chang for you. Before I asked you any questions about how you make choices, I asked you first if it was ok to ask you the questions. I also asked your family or the person who helps you make decisions if it was ok to ask you the questions.

The type of questions I asked were about if you make your own choices and do the things you decide to do. If you feel sad now or later from answering the questions tell someone who works in your home that you want to talk to Marion Kalman. Her telephone number is (714) 996-8864. She is trained to help people who feel sad feel better. If you don't want to talk to Marion it is ok. You can talk to anyone you want to but please talk to someone because feeling sad is not fun and talking to someone can help you feel better.

Some of the good things you can get from answering the questions about how you make choices are learning a little bit about new ways of making your own choices and new ways of doing the things you decide to do. If you decided to learn how to use the machine to answer the questions you have already learned a new way to talk to people. If you liked using the machine to talk to people you can tell the people who work in your home that you liked it and they can get a machine like that for you. Sometimes it can take a long time to get the machine but it will come sooner or later just keep asking. If you want to learn more about how to make choices and how to do the things you decide to do you can tell the people who work in your home and they can teach you about it because when I am done with my project I am going to give them a copy of my project and they can go over it with you but it will not be done until next year around this time.

If you decide that you don't want me to give your answers to my teacher its ok just tell the people who work in your home and they will tell me. I will not use your answers and you don't have to worry about anyone being angry with you or getting in trouble because this is not something you have to do. It was very nice to get to know you.

DEBRIEFING STATEMENT

Your family member or the person you are a conservator for has participated in a study comparing self-determination between residents of Intermediate Care Facilities for Developmental Disabilities Habilitative type who are nonverbal and verbal. This study was conducted by Karen Mahon under the supervision of Dr. Chang at (909) 880-5184. Informed consent was obtained by participants, legal conservators, Inland Regional Center counselors and/or family members prior to residents participating in this study.

This study asked several questions regarding issues such as autonomy, self-regulation, psychological empowerment and self-realization. Due to the nature of these questions, your family member or the person you are a conservator for may feel the need to speak with someone regarding feelings of issues that the questionnaire may have provoked. If he/she wish to discuss this please contact the Marian Kalman Ph.D. at (714) 996-8864 or another support person.

Some of the benefits of participating in this study may include being able to express concerns your family member or the person you are a conservator for have about self-determination in a public manor. If your family member or the person you are a conservator for choose to use the communication device to complete the survey he/she may learn a new way to communicate. Your family member or the person you are a conservator for may also learn what some of the components of self-determination are and how to increase his/her own self-determination. If you, your family member or the person you are a conservator for would like more information on self-determination please contact the administrator of the facility after June 2004 for a copy of the research project.

APPENDIX D

LETTER'S OF APPROVAL

Subj:
The Arc of the United States
Date:
05/14/2003 11:04:13 AM Pacific Daylight Time
From:
privett@thearc.org
To:
mahonch@aol.com
Sent from the Internet

Carrie,

Consider this e-mail message to be formal permission to use materials from The Arc's web site at www.thearc.org as you see fit. Please credit The Arc of the United States where appropriate.

Feel free to let me know if you need anything further.

Best regards,
Chris Privett
Communications Director
The Arc of the United States
1010 Wayne Ave. Suite 650
Silver Spring, MD 20910

Contributions built The Arc. You can help The Arc fulfill its mission by making a contribution at www.TheArc.org Click on "Donate Now" in the lower left corner of the site. Thank you for your support!

Rockcreek, Inc.
1814 South Commercenter West, Suite F
San Bernardino, California 92408

May 25, 2003

Social Work Department
California State University
San Bernardino
5500 University Parkway
San Bernardino, CA 92407

RE: Karen Mahon – Proposal for Research Project

I am writing in support of Karen Mahon's proposal for a research project relating to residence of ICF-DD-Hs.

Please be advised that our agency will assist Karen to insure the success of her research project. This will allow access to client residing in Rescare facilities.

Sincerely,

Carl Carney
Quality Assurance Manager

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