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ABSTRACT

DEFINING AND MEASURING COMMUNITY INCLUSION IN THE LIVES OF PEOPLE WITH MENTAL RETARDATION

By

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The term community inclusion is widely used when discussing the lives and services designed for people with mental retardation. Despite the frequent use of the term and frequent programmatic attempts at achieving it, there have been few attempts to define and measure this complex construct. The lack of investigation of this construct has made it difficult to determine what factors contribute to one's experience of community inclusion. The purpose of this exploratory study was to operationalize and measure community inclusion by identifying four components that were hypothesized to contribute to the experience. The participants in the study were 126 consumers of services at Clinton-Eaton-Ingham Community Mental Health-Community Services for the Developmentally Disabled located in Michigan.

Community inclusion was operationalized using four components suggested in the literature: integration, social support, social role, and choice. Measures for each of these components were determined. To examine the utility of this multi-dimensional measurement approach the reliability of the measures were examined. Cronbach alphas were used to examine the internal consistency of the measures. A correlation analysis of the relationship among the four components was also performed to better understand the components as a comprehensive concept of community inclusion. The relationship

between community inclusion and quality of life was also examined. Quality of life was measured using a subjective measure of life satisfaction and the objective measures of adaptive behavior and social indictors. To further explore the value of the measures the scores on each measure and the total of all measures were compared by agency program. The participants in this study were receiving services from at least one of two programs, Vocational Services or Transitions.

This research examined the cogency of this operational definition by making the following hypotheses: (1) The measures for each of the components of community inclusion (community integration, social support, social role and choice) will be internally consistent; (2) There will be a statistically significant positive relationship between proposed components of community inclusion: community integration, social role, social support, and choice; (3) There will be a statistically significant positive relationship between community inclusion and quality of life; and (4) Participants from Vocational Services will have statistically significant higher scores on measures of community inclusion than participants from Transitions.

Results from this study indicate some strengths and weaknesses in the operationalization and measurement of community inclusion. In response to hypothesis one, the alpha level for the measures of community integration (Community Activity and Participation Checklist), social support (Social Support Self-Report) and choice (Choice Questionnaire) all indicated adequate internal consistency. The corresponding alpha for the measure of social role (Social Role Checklist) however, would be considered insufficient.

There were statistically significant relationships found between the four measures of community inclusion. Every relationship between two components was found to be statistically significant except for the relationship between choice and social support. The relative strength of the correlation coefficients attained between the four measures also indicates that the four separate measures are not measuring the same construct.

There was a statistically significant relationship between the total score of community inclusion and subjective quality of life (life satisfaction) as measured on the Consumer Satisfaction Survey. There were also statistically significant relationships found between subjective quality of life community integration and social support.

A Pearson correlation analysis indicated that there was a significant relationship between adaptive behavior as measured on the ICAP and community inclusion, the total of the four components. The ICAP was also positively correlated with the measures of choice and social role.

Statistically significant differences in levels of community inclusion between participants from Vocational Services and Transitions were determined. The demographic variables from the two groups were first tested to assure that they are actually two different groups. Participants from Vocational Services had higher ICAP scores, less paid support, more social roles, and more opportunity for choice. Participants from Transitions indicated lower ICAP scores, greater paid support, fewer social roles, and lower opportunity for choice-making. Participants from Vocational Services scored higher on all of the community inclusion measures.

In summary, this research proposed that community inclusion could be operationalized by the sum of four components: (a) community integration, (b) social

role, (c) social support, and (d) choice. The findings from this study provided some knowledge from which to build. These measures appear to be promising tools for helping community agency staff assess individual inclusion needs so steps may be taken to increase individual community inclusion. While the field of rehabilitation as well as the field of mental retardation supports a philosophy of community inclusion, it is important that it continue to be operationalized and subsequently measured. A need for future research was revealed and directions are emphasized.

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TABLE OF CONTENTS

CHAPTER 4

CHAPTER 5

APPENDIX

LIST OF TABLES

Chapter 1

INTRODUCTION

People with mental retardation collectively make up one of the largest rehabilitation populations and most prevalent disability populations in the United States (Rubin & Roessler, 1995). The 1990 census estimated that between 6.2 and 7.5 million people in the United States have mental retardation, cutting across lines of race, ethnicity, and socioeconomic levels (Bureau of the Census, 1995).

The mental retardation movement has been described as one of the great social movements of the 20th century (Braddock, 1994). Throughout this century, the field has been in transition to improve the lives of people with mental retardation. Legislation, such as the Developmental Disabilities Act (1976), PL 94-142 (1975), IDEA (1990), ADA (1990), and the Rehabilitation Acts (1973) have both initiated and supported progress (Jenkins, Patterson, & Szymanski, 1992; Rubin & Roessler, 1995; Wolfe, Kregal, & Wehman, 1996; Wright, 1980). Philosophical changes such as normalization, least restrictive environment, integration, and inclusion indicate the change in the perception of capabilities and value placed on the lives of these people (Bruinicks, Kudla, Hauber, Hill, & Wieck, 1981; Condeluci & Williams, 1997; Maki & Riggar, 1997). Both legislative and philosophical shifts have promoted services changes, specifically deinstitutionlization (Olney & Salamone, 1992; Racino, 1994). One of the key changes beginning in the 1970s for this population has been the shift from providing services within an institutionalized setting to a community setting typically referred to as a community mental health agency or community services (Levine & Perkins, 1987).

At the initial onset, the purpose of deinstitutionalization was attributed more to funding practices than philosophical ideals (Levine & Perkins, 1987). Unfortunately, because of this emphasis, many people found themselves in a situation where they left a mental retardation facility to live in a community based setting that continued to follow the same guidelines and practices of the institutional setting. This initially led to increased costs for care, supervision and housing (Jacobson & Burchard, 1992).

Traditionally, community agencies would evaluate quality through an examination of service delivery practices directed toward care and safety. Practices and characteristics that foster client independence, physical access to the community, participation in the community, and individual adjustment were not assessed (Jacobson & Burchard, 1992). In the 1990s many community agencies have begun to look at a wider variety of outcomes and to consider consumer satisfaction as one of them.

These legislative, philosophical, and service changes have led to a current overriding focus of increasing community inclusion (Storey, 1993), and improving the quality of life for people with disabilities in all aspects of their lives, including work, education, living arrangements, socialization, and leisure (Halpern, 1994; Landesman, 1986; Walker, 1988). The concepts of community inclusion and quality of life have assumed greater importance in current mental retardation literature. The two concepts also have commonalties that are not related to their meaning. While both terms have been identified as current "buzz" words within the field, both community inclusion and quality of life are considered difficult to define and measure. There is also a presumed causal link both in theory and practice, between these two concepts although there is no research evidence to support such a link (Condelucci & Williams, 1997).

The term community inclusion is often used interchangeably with community integration (Bricker, 1995; Magis-Agosta, 1994). Researchers have recognized that community inclusion is a complex concept to define and to achieve it in a way that benefits both people with and without disabilities (Bricker, 1995; Taylor, 1992). Magis-Agosta (1994) noted that community inclusion is achieved not simply through physical presence in the community, but with the opportunity for self-determination, and for cultural and social inclusion. Thus, community inclusion is intended not only to integrate an individual physically in a community environment, but also promote the individual's experience of belonging to it through the establishment of relationships and a social role within the environment. Community inclusion, requires a more precise definition than that found in current service systems, so that this practice is based on the social needs and experience of the individual.

Examining the various use of the terms community integration and community inclusion and attempting to differentiate the two may appear to be a simple case of semantics. But, as Storey (1993) noted, a consensus in defining and measuring the construct is necessary to guide research and service delivery at both the individual outcome level and the more global level, which influences social policy. Attempts have been made to measure community inclusion, but this research has tended to use a one dimension, outcome based approach, typically focusing on activity in terms of location, frequency, and duration (Magis-Agosta, 1994; Taylor, 1992). Such approaches fail to examine the individual's preference or choice regarding an activity or experience, how the individual defines the meaning of the activity or experience, the quality of participation, and the perceived value of the experience (Jacobson & Burchard, 1992).

Thus, despite the attention paid to strategies to increase community inclusion, little attention has been paid to defining and measuring it (Storey, 1993).

Due to the lack of investigation of this construct it is difficult to determine exactly what the factors are that contribute to one's experience of community inclusion. Storey[1] proposes to define this construct as having four components: physical integration, social integration, relationships, and social networks. Physical integration refers to the physical presence in the community. This is a component that seems to be readily accepted throughout the literature. Social integration is defined as "regular access to interactions with individuals without identified [disabilities] and regular use of normal community resources (Will, 1984, p. 2, as cited in Storey, 1993). Relationships refers to social support and can be measured in terms of quantity (number of relationships, frequency of contact, length of relationship, etc.), structure (reciprocity within the relationship), and function (role within the relationship such as friend, parent, sibling, co-worker, etc.). Social networks are difficult to define as stated by Storey (1993) and appear to be strikingly similar to friendships. Storey defines social networks as repeated contact with a number of people who would also identify an existing relationship. While Storey's (1993) theoretical argument for the use of the four components discussed may be reasonable, there has been no empirical evidence that can validate this proposition.

Other scholars have identified other human needs that may be additionally important components of community inclusion. Maslow (1954) in his discussion of hierarchy of needs and Wolfensberger (1983) in his discussion of normalization and social role valorization both touch on examples of psychological needs such as the need

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[1] Storey (1993) refers to the construct as community integration rather than community inclusion. In order to maintain continuity, this research will use the term inclusion to present his ideas.

to affiliate with others, the need to be accepted, and the need to belong. Maslow and Wolfensberger's theories suggest that having a social role is an important component of inclusion.

Thus far three constructs have been identified as possible components of community inclusion: community integration, social support, and social role. While these are components of community inclusion that may contribute to the experience of community inclusion, this is not an experience that can be done to the individual. Therefore, choice is an important construct to consider as a component of community inclusion (Bullock & Mahon, 1992).

Proponents of community inclusion believe that it will improve the quality of life for people with developmental disabilities (Jacobsen & Burchard, 1992; Storey, 1993). Quality of life has been identified as one of the new (Landesman, 1986) and important issues of the 1990s (Vandergriff & Chubon, 1994) with regard to services for people with mental retardation. In fact, quality of life has also been identified as an important current issue in the lives of all people with disabilities (Schalock & Kiernan, 1990).

However, quality of life is also a difficult construct to define (Felce & Perry, 1995; Halpern, 1994; Jacobson & Burchard, 1992; Landesman, 1986). It has been defined as both a subjective and objective construct (Fabian, 1990; Halpern, 1994; Taylor & Bogdon, 1990; Taylor & Bogdan, 1996). Halpern (1994) stated that the subjective quality of life refers to the individual's point of view. As a subjective construct, self-reported life satisfaction or subjective well being is typically what is measured (Day & Alon, 1993; Fabian, 1990; Schalock, 1990; Schalock, 1994; Taylor & Bogdan, 1990; Taylor & Bogdan, 1996). As an objective measure, adaptive functioning and/or social indicators (such as socioeconomic status, number of activities involved in, or number of hospitalizations) are typically used as measures (Day & Alon, 1993; Fabian, 1991; Felce & Perry, 1995; Harner & Heal, 1993). Halpern (1994) referred to objective quality of life as society's point of view with the perspective coming from either the individual or another person. Recent research and literature has become concerned with the quality of life of persons with mental retardation, but few studies have relied on the individuals themselves to provide such information (Jacobson & Burchard, 1992).

The causal link between increased community inclusion and enhanced quality of life has been suggested in the literature (Harner & Heal, 1993; Jacobson & Burchard, 1992; Sands & Kozleski, 1994; Schalock and Kiernan, 1990; Storey, 1993). Scholars have also provided theoretical support for community inclusion as a determinant of improved quality of life (Condeluci & Williams, 1997; Felce & Perry, 1995; Halpern, 1994). Nevertheless, this literature search found no empirical evidence that experiencing community inclusion as defined as a multi-component construct does indeed improve quality of life whether measured subjectively or objectively.

Statement and Significance of the Problem

Despite efforts introduced by deinstitutionalization and community integration, conditions of living and working are not changing rapidly enough to keep up with the changes in attitudes, aspirations, and values of people with disabilities (Schalock & Kiernan, 1990). Attitudes, values and aspirations of people with disabilities relate to the individual's subjective evaluation of quality of life. Mere physical integration within the community environment is not necessarily congruent with the needs and wants of many people with mental retardation and therefore, this integration is not proving to be a sufficient means to significant improvement in quality of life (Magis-Agosta, 1994; Schalock & Kiernan, 1990).

Numerous programs and services that have attempted to move toward increased community inclusion and enhanced quality of life. Yet a significant proportion of people with mental retardation continue to be marginalized, stigmatized, segregated and disenfranchised in regards to living arrangements, daily activities, work, and leisure (Braddock, 1994; Bullock & Mahon, 1992; Gliner & Sample, 1994, Miller & Keys, 1994). As Millington, Szymanski, and Hanley-Maxwell (1994) stated, these individuals are often under-used in the labor market and continue to receive government assistance. Furthermore, Gliner and Sample (1994) have identified the need to increase community integration, community inclusion, and quality of life for people with mental retardation receiving either sheltered or supported services.

Despite the frequent use of the term community inclusion and the frequent programmatic attempts to achieve it, there have been few attempts to either define or measure community inclusion as a complex multi-dimensional construct nor to evaluate its impact on quality of life. When measuring community inclusion, researchers and program evaluators have typically focused only on an indication of physical presence in the community.

It is therefore necessary that research efforts consider a more holistic and complete definition for community inclusion that includes and utilizes all of the central multiple factors involved, including community integration, social role, social support, and choice. It also appears that it would be valuable to measure quality of life for people with mental retardation using their own perspective in order to understand the relationship between community inclusion and its various components and an individual's perceived quality of life.

Purpose of the Study

The purpose of this study was to define community inclusion as well as expand our understanding of the experience for people with mental retardation. Community inclusion will be operationalized using four components suggested in the literature: integration, social support, social role, and choice. Measures for each of these components were developed. This research examined the cogency of this operational definition by asking the following research questions:

1. Are the measures for each of the components of community inclusion (community integration, social support, social role and choice) reliable?
2. Is there a relationship between proposed components of community inclusion: community integration, social role, social support, and choice?
3. Is there a relationship between community inclusion and quality of life?
4. Is there a difference in scores on measures of community inclusion for people in different agency programs?

Definition of Terms

Clinton-Eaton-Ingham (CEI) Community Mental Health (CMH) Community Services for the Developmentally Disabled (CSDD) or CEI-CMH-CSDD: This is a tri-county community mental health agency located in the state of Michigan that specifically serves people with developmental disabilities. Services include housing, health care, and vocational.

Person with Mental Retardation: An individual who has substantial limitations in present functioning, characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental Retardation occurs before the age 18.

Consumer: Any individual who is currently receiving services from CEI-CMH-CSDD.

Community Inclusion: Community inclusion is a psychosocial and holistic experience which includes but is not limited to: (a) community integration, (b) social role, (c) support and (d) choice.

Community Integration: This is the time an individual experiences a physical presence in an integrated community setting.

Social Role: Social role includes the roles that one holds within the community.

Choice: The opportunity to make "an unforced selection of a preferred alternative between two or more options" (Stancliffe & Abery, 1997, p. 160).

Paid Support: A person who is a paid disability service provider and who provides assistance, feedback, companionship, or contact to assist a person with a disability participate in a work or community setting.

Natural Support: A person who is not a disability service provider but who provides assistance, feedback, companionship, or contact to assist a person with a disability participate in a work or community setting.

Quality of Life: Quality of life is defined as the subjective self-reported expression of life satisfaction and the objective assessment of adaptive behavior and social indicators (i.e., health, income, use of adaptive equipment).

Assumptions and Limitations

Generalizability

Given that this study was conducted exclusively with a sample from a Mid-Michigan community mental health agency, there is an obvious limitation to the generalizability of the results. One assumption is that this community mental health agency is similar to other community mental health agencies in the services that are provided their consumers. Despite reported differences in the community mental health boards across the state of Michigan, the provision and types of services are standard and regulated (R. Coelho, personal communication, June, 1998). Another assumption has been made that the individuals in this sample are similar to consumers of other community mental health agencies. During this research period there was a statewide implementation of the Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986). This implementation provides a uniform standard to qualify people as far as need for services as well as a standard for the provision of services.

Validity of information received

A major assumption of this study concerns the validity of the responses of persons with mental retardation. Previous research has noted several issues in the assessment of people with mental retardation. These issues include acquiescence (Heal & Chadsey-

Rusch, 1985; and Matikka & Vesala, 1997), test-retest reliability, responsiveness, consistency, and informant reliability (Heal & Sigelman, 1996).

Acquiescence is the tendency to respond affirmatively regardless of question. Literature has suggested that this is a threat to data from people with mental retardation (Heal & Sigelman, 1996; Matikka & Vesala, 1997). Acquiescence is assumed to arise from three sources: attributes of the subject, properties of the items or the test, or the aspects of the situation. Evidence has shown that acquiescence is related to lower education and intelligence. This threat should be considered in regard to each interview. If the researcher had suspicion of acquiescence, it could be evaluated by asking questions as suggested by Stancliffe (1997). The evaluation would consist of the question(s) being asked in two ways. For example, "do you live by yourself?", "do you live with someone?"

Sigelman, Schoenrock, Budd, Winer, Spanhel, Martin, Hromas, and Bensberg (1983) found that test-retest reliability was at 87% when asked "yes or no" although the majority of the responses were "yes" possibly indicating acquiescence. This research also found that given four option multiple choice questions yielded a 72% test-retest agreement rate. This same study found that open-ended questions asked one week apart rarely yielded the same responses on both occasions. The researchers mention that while overall reliability seems high, reliability is also hard to determine without determining the general accuracy of the responses. Responses to open-ended questions are typically under-reported in comparison to responses to "yes/no" questions. For example, more daily activities are reported on questions that require a "yes/no" response to a list of activities than to an open-ended question soliciting daily activities.

Researchers have found that responsiveness to questions on the part of people with mental retardation varied according to the intellectual level of the individual (Sigelman, Winer, & Schroenrock, 1982). Responsiveness also varies given the type of question. Questions that ask for a "yes" or "no" response typically produce higher rate of responsiveness. Verbal multiple-choice questions and open-ended questions have typically proven to be the most difficult for people with cognitive disabilities to answer (Heal & Sigelman, 1996). To increase responsiveness, variation in methods of asking and answering questions can be used. These variations typically involve the use of pictures that can elicit non-verbal responses (Sigelman & Budd, 1986).

Ability to measure quality of life

Fabian (1992) in a discussion of measuring quality of life states that "even instruments with demonstrated reliability and validity, when used to measure complex and multifaceted constructs such as quality of life, are subject to cautions concerning their use and interpretation." Rather than abandoning or avoiding the study of quality of life outcomes, she suggests that to continue to promote progress in this area, researchers must become familiar with quality of life definition and measurement issues, acknowledge the issues, and interpret the results with caution. Therefore both the nature of the subject matter being assessed and the population whose responses are being solicited, present challenges to the quality of data. For these reasons, the findings will be considered tentative and exploratory in this study.

Chapter II

REVIEW OF LITERATURE

To inform this research, literature was reviewed within the fields of mental retardation, developmental disabilities, rehabilitation, rehabilitation counseling, psychology and special education to develop a context for this study. The following areas were identified as important in informing this research: (a) mental retardation, (b) the history of services for people with mental retardation, (c) community inclusion, and (d) quality of life.

Mental Retardation

The American Association on Mental Retardation (AAMR, 1992) defines mental retardation as follows: "Mental Retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental Retardation manifests before age 18" (p. 5). This definition attempts to prevent the labeling and subsequent stigmatization of individuals who may score in the range of retardation on an intelligence test. It also identifies possible incongruence between an individual's measured level of intelligence and the ability to function within the norms of the home, school, or neighborhood environment (Sharpton & West, 1996).

There are four important assumptions made regarding this definition. First, assessments must take into consideration cultural or linguistic diversity as well as individual communication and behavioral differences. Second, assessments consider the community context, specifically the skill level typical of the same age peers. Third, assessments consider skill strengths especially in comparison to identified deficits. Finally, it is assumed that when given the appropriate supports, there will be improvement in areas that are related to life functioning (Langone, 1996).

Historically, mental retardation was described by levels of severity (e.g., mild, moderate, severe, profound) which were defined by the deviation from the norm of individual's measured level of intelligence (Langone, 1996). The current AAMR (1992) definition no longer defines individuals by level of severity. Individuals are classified by the levels of support in their lives. The four levels are: (1) episodic or short term during the life span; (2) limited support over longer periods of time; (3) extensive support provided as a regular service; and (4) pervasive support that is constant and intense and may even be life-sustaining (Langone, 1996). While these levels of support seem to parallel the categories of mild, moderate, severe, and profound, they are fundamentally different. In line with the AAMR 1992 definition of mental retardation, the levels of support approach attempts to prevent labeling based solely on IQ. This approach also recognizes that labels do not necessarily predict what individuals need (Langone, 1996) to ultimately improve the quality of life that is experienced. Rather, these categories look at the individual's needs and subsequently how to provide support for the identified needs in order to reach life goals (Langone, 1996). Reception toward these changes in categorization has been favorable, although it is doubtful that use of the historical categories (e.g., mild, moderate, severe, profound) will be totally replaced by the levels of support. This change will be difficult given that they have been a standard for so long and that they provide a better understanding of an individual's cognitive functioning.

History of Services for People with Mental Retardation

While life in the United States in general has experienced change during this century, there have also been tremendous changes in the lives of people with mental retardation during this time. These changes can be attributed to legislation, philosophical changes, paradigm shifts, and philosophically based interventions.

Legislation

Legislation in the past thirty years has been important in attempting to improve the lives of people with mental retardation. The following legislation has been directed toward virtually every area of service provision, particularly educational, residential, and vocational (Wolfe, et al., 1996). Starting in 1970, The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) introduced the concept of developmental disabilities, which includes mental retardation, as a unique segment of the disability population (Wright, 1980). In 1971, Title XIX of the Social Security Act (P.L. 92-223) required intermediate care facilities for people with mental retardation to provide "active treatment." This required the time of the people served in these facilities be "programmed" throughout their waking hours. In 1975, The Education of All Handicapped Children (P.L. 94-142) guaranteed a free and appropriate education to all children in the "least restricted environment" (Rubin & Roessler, 1995; Wright, 1980). This was the beginning of "mainstreaming" and integration into the regular classroom setting for many children with disabilities who were segregated in "special" educational settings.

In 1990 there were three key pieces of legislation that impacted individuals with developmental disabilities. First, The Developmental Disabilities Assistance and Bill of

Rights Act, emphasized empowerment for people with developmental disabilities along with protection and advocacy (Wolfe, et al., 1996). The Education of the Handicapped Act Amendments (P.L. 101-476) changed the name of the law to the Individuals with Disabilities Education Act (IDEA) to reflect "person-first" language. It also expanded the definition to include students with traumatic brain injury, autism and projects for students with serious emotional disturbances. There was also an emphasis placed on transition planning from school to work (Rubin & Roessler, 1995; Wolfe, et al., 1996). The Americans with Disabilities Act (ADA) offered civil rights to individuals with disabilities, required reasonable accommodations of employers, and also extended rights to accessible employment settings, public transportation, and public establishments (Wolfe, et al., 1996). In 1992, the Rehabilitation Act Amendments (P.L. 102-569) provided support for the service systems which assisted employers in finding assistance and expertise to meet the reasonable and appropriate job accommodations of the ADA. It also established a basis in the adult service system for accomplishing transition preparation, planning and implementation as called for in IDEA. One other important result is that it put the abilities and choices of people with disabilities first as it challenged the service systems and community to support the individual's efforts to work, live, and participate in the community.

Philosophical Change in Services Toward an Inclusion Model

The crux of various paradigms we see today in the field of mental retardation was initiated in the late 1960s with Wolfensberger's principle of normalization (Wolfensberger & Tullman, 1991). "Normalization implies as much as possible, the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people" (p. 202).

Philosophical changes have subsequently influenced service. In the 1960s there were fewer than 100 community residences and virtually no community services for people with mental retardation (Braddock, 1994). The institutional per diem was less than $10 (Department of Health Education, and Welfare, 1968, as cited in Braddock, 1994). The landscape of services is quite different today. Thus the theory of normalization has had great impact on the lives of people with mental retardation, particularly with regards to deinstitutionalization. Nationally, deinstitutionalization over the past 25 years has changed services for people with mental retardation by systematically dismantling bureaucratic structures while creating a system of community services (Bradley, 1994). The advocates of deinstitutionalization for people with mental retardation assumed that greater happiness would be the inevitable outcome. However, it is important to remember that while research has shown that deinstitutionalization has provided better care and physical services, there is also evidence that community living "did not provide a social or psychological milieu" much different than the segregated institution (Bradley, 1994). Heal (1980) stated that normalization has "pervaded the development of community services." (p. 39)

With regards to paradigm shifts, Condeluci and Williams (1997) recognized the importance of the history of rehabilitation in the development of the concept and the understanding of the importance of community inclusion. Early in the history, the goal of rehabilitation was to "fix' people with disabilities. This has evolved to the current philosophy that identifies people with disabilities as "consumers". The medical model, which was the early model of rehabilitation, identified people as "sick, ill, deficient, or defective." (p. 113) The perception was that there was something wrong with the person. The treatment plan was designed to cure the person. Another key aspect of this former model was that it was both designed and administered by the rehabilitation professionals who were considered experts. The model devalued the person with a disability and the individual would be made to feel inappropriate and inadequate in roles in society.

In a similar description of the shift, Racino (1994) compares the differences between the Rehabilitation Paradigm, the Independent Living Paradigm, and the Support/Empowerment Paradigm in terms of the definition of the problem, locus of the problem, social role, solution to the problem, and desired outcomes. Table 1 (Racino, 1994) presents a framework of this paradigm shift. The shift toward a support/empowerment paradigm exemplifies the increasing desire by consumers and advocates toward an inclusive society where responsibility and power are shared and genuine alliances are formed among people with disabilities, professionals, and community members. The concept of support can be described as "an act or set of actions, am attitude or set of values, a feeling, or personal experience, a set of standards or expectations, a relationship descriptor, and an expected goal or accomplishment (Racino, 1994, p. 173). In terms of an agency perspective, support can be defined as formal/paid, or informal/unpaid/natural. The developmental disability field is moving toward community life utilizing formal support with the goal of developing informal supports.

As a result of several factors, which include a lack of opportunity and power (Keys, Balcazar, Bartunek, & Foster-Fishman, 1995), people with mental retardation continue to be marginalized and stigmatized within American society (Miller & Keys, 1996). There have been many programs and interventions designed to help consumers adjust to these paradigm shifts and to also enable them to take responsibility for their lives. There have been many programs or interventions developed to address these philosophically based changes. The promotion self-advocacy has been an attempt at identifying and addressing this need. Cone (1994) has described self-advocacy as seeking one's rights, including human, civil, or legal. Self-advocacy can vary in terms of structure. "Formal" self-advocacy tends to be more structured and addresses change through a system typically legal or legislative. "Informal" self-advocacy is much more individualistic, while utilizing and fostering concepts such as empowerment (Miller & Keys, 1996; Zirpoli, Wieck, Hancox, & Skarnulis, 1994) and self-determination. Since 1973 the self-advocacy movement has continued to grow providing training, information and support to people with mental retardation and their families (Browning, Thorin, & Rhoades, 1984). One such training program found in the United States is Partners in Policymaking, "a program designed to provide information, training, resources, and skill building in the area of developmental disabilities to families of young children with disabilities. The program's goals include educating people about historical perspectives, current issues, and state-of-the-art approaches; informing them about how policies are made at local, state, and national levels; and empowering people to pursue their own agenda so that they may obtain the best available services" (Zirpoli, et al., 1994, p. 423).

Table 1
Comparison of the Rehabilitation, Independent Living, and Support Paradigms.

Focus	Rehabilitation Paradigm	Independent Living Paradigm	Support Paradigm
Definition of the Problem	Physical impairment, lack of vocational skill, psychological maladjustment, lack of motivation and cooperation	Dependence on professionals, relative, and others; inadequate support services; barriers including economic architectural, and environmental	Attitudinal political, economic, and administrative barriers to societal participation, inadequate supports within society.
Locus of the problem	In the individual	In the environment, or in rehabilitation process	In society or environment; in rehabilitation process
Social Role	Patient or client	Consumer	Co-worker, community member, neighbor
Solution to Problem	Professional intervention	Peer counseling, advocacy, self-help, consumer control, removal of barriers and disincentives	Redesign schools, homes, work places, health care, transportation, and social environments to include all.
Who is in Control	Professionals	Consumer	People in alliance with each other
Desired Outcomes	Maximum daily activities, gainful employment, psychological adjustment, improved motivation, completed treatment	Self-direction, least restricted environment, social and economic productivity	Pluralistic society inclusive of all people; quality lives as defined by people themselves, self-direction embedded in collaborative decision making and solving problems

Self-Advocates Becoming Empowered, was formed in 1991 in an attempt to nationally unite grass root organizations. Such groups include People First, People in Action, The Advocates Voice, and Speaking for Ourselves (Miller & Keys, 1996). These groups may not share one name but they do share a common purpose and ideology as stated by Self-Advocates Becoming Empowered. This basic mission is to "teach individuals with developmental disabilities to speak out for their beliefs while learning about their rights and corresponding responsibilities as citizens in the United States" (Miller & Keys, 1996, p. 313).

Community Inclusion

In this research, community inclusion is being defined as a psychosocial construct. In order to understand this perspective of community inclusion, it is helpful to have knowledge of the following components: (a) community integration, (b) social role, (c) choice, and (d) support.

Community Integration

Community integration is one component of the more complex construct, community inclusion. Community integration was initially intended to be an approach to accomplish the desegregation of people with disabilities (Racino, 1994). There are a variety of historical and conceptual definitions that describe integration. Educational systems were the first to begin to define and address integration by providing classroom mainstreaming opportunities for children with disabilities, including students with mental retardation. These children were given the opportunity to receive their education in a "regular" classroom while continuing to receive needed special education services (Gearheart, Weishahn, & Gearheart, 1988). Racino (1994) states that community integration has also been viewed as the establishment of lifestyle and routine, similar to that of others, usually service workers. Racino (1994) also points out that "To some extent, community integration in practice was something that people without disabilities do to people with disabilities..." (p. 186), thus identifying the contradiction between theory and practice. While community integration has as its purpose the desegregation of people with mental retardation, the reality is that segregation still exists just in a different environment. Without social interaction between the person with the disability living in the community and other people in the community segregation continues to exist at some level (Storey, 1993).

Wolfensberger and Tullman (1991) delineated the difference between physical integration and social integration. Physical integration is merely physical presence in the community. This has been a concern with the limitations of deinstitutionalization and mainstreaming where physical presence is achieved in the community (housing) or the classroom (education) but, does not necessarily result in social participation.

In practice, programs serving a population of individuals with mental retardation are often described as inclusive or integrative if the individual is given the opportunity to leave the institution or sheltered setting for a time period. This author witnessed this practice. For example, the terms community inclusion and community integration, have been used when large groups (8-10) of people with mental retardation were taken on van rides but never leave the van. The terms have also been used to describe trips to malls, bowling alleys, movie theaters, etc., where the agency staff exposes the group to an activity in a public environment but the experience of the participants continues to be segregated.

This social segregation seems to persist for several possible reasons including: (a) lack of choice for the individual, either prior to or during the experience, due to inability to make choices by the individual, lack of provider resources to make choices available, or attitudinal barriers on the part of the staff or individual concerning the individuals ability to make choices; (b) prevention from appropriate interaction with community members during the experience possibly due to either behavioral issues that the individual may possess or attitudinal barriers created by the staff or community members; or (c) obstruction from full participation in the activity due to variables such as group size, lack of available staff, or environmental barriers.

Bercovici (1981), who stated that many studies have identified the degree to which people experiencing deinstitutionalization have been successful in terms of adapting to the community, supported this observation. Unfortunately, less is known about the nature of the contacts in the community and the phenomenon of community as defined by the person with a developmental disability. Adjustment to the community has frequently been operationally defined as staying out of a public institution, staying in alternative settings, or avoiding other forms of public supervision and assistance (Bercovici, 1981).

Social integration, as defined by Wolfensberger and Tullman (1991), encourages "devalued" people to participate in the community within a social context rather than simply a physical context in order to gain value. They have stated that it may actually be harmful for large numbers of people to be sent out of institutions and into society without providing the means to become valued members of society.

While attempts have been made to measure community integration, the attempts have had a tendency to be one dimensional, typically focusing on the activity in terms of location, frequency, and duration, rather than how the individual defines the experience in terms of participation, value of experience, and social role. The movement from institutionalization to life in the community has proven to be physically and medically beneficial for people with mental retardation. However, community integration in the physical sense within the community environment does not guarantee that the person will experience community inclusion in the full sense because the person may continue to experience social segregation.

The Importance of Social Role

Maslow (1954), the personality theorist, proposed that there is a hierarchy of human needs. These needs operate from one of three levels: fundamental, psychological, and self-actualization (Wortman & Loftus, 1988). Fundamental needs are those needed for basic survival such as food, water, and shelter from the elements. Maslow contended that people must first meet their most elemental needs before they can address their needs at a higher level. If these fundamental needs are met, the individual advances to meeting psychological needs (i.e., belongingness and love) (Newman & Newman, 1991). Examples of psychological needs are the need to affiliate with others, the need to be accepted, and the need to belong. Psychological needs also include needs associated with self-esteem such as the needs to achieve, to be competent, and to fill a social role (Wortman & Loftus, 1988). Self-actualization needs specifically relate to the needs to fulfill one's potential (Wortman & Loftus, 1988).

While the specific aspects of Maslow's theory have not always supported (Paulis & Garcia, 1991; Wortman & Loftus, 1988), the basis of the theory which assumes that needs motivate behavior, and more specifically one's task performance has been validated (Wortman & Loftus, 1988). Maslow's theory also relies on the basic belief that the individual has the ability to make choices that will impact his or her life.

Given current service practice, it is probable that most individuals with mental retardation who are in a service system have met their survival needs, whether they have met these needs themselves or have them met by others. If one can assume the validity of Maslow's theory of the hierarchy of needs and it's application to individuals with mental retardation, then one could also assume the emergence of psychological needs for people with mental retardation given that more basic needs are met.

Wolfensberger and Tullman (1991) stated that people with disabilities are often "devalued" and are typically a) segregated from society, b) grouped with other "devalued" people, and c) served by less competent workers than "valued" people. They stated:

> "Normalization requires that a devalued person or group has the opportunity to be personally integrated into the valued social life of society. Devalued people would be [able] to live in normative housing within the valued community and with valued people; be educated with their nondevalued peers; work in the same facilities as other people; and be involved in a positive fashion in worship, recreation, shopping, and all other activities in which the members of society engage." (p. 213)

In the field of mental retardation, the concept of social role was introduced in 1982 (Elks, 1994). Wolfensberger (1983) identified the need that all people have to play roles in society. The greater the exposure and opportunity (integration), the greater the chance that the individual will be assimilated into society. Social-role valorization is the means of attaining social roles in the attempt to increase one's value in society (Condeluci & Williams, 1997).

Theorists (Maslow, 1954; Wolfensberger, 1983) identify the importance feeling valued by holding social roles in our society. . Developing social role is the link to developing relationships, particularly friendships. Condeluci and Williams (1997) state that "people become known more for the relationships they develop than for how they perform or function" (p. 112). Thus, it is not sufficient to merely have a physical presence within the community, or even simply to interact with others. One must form relationships that help to develop and define the individual's social role. Therefore, the development of social role has bearing on community inclusion and has been determined to be a necessary component in this construct.

Choice

Adults in the general population rarely have other people making day to day decisions for them, such as when they go to bed, what they eat for meals, what they should wear and who they should spend free time with (Pierce, Luckasson, & Smith, 1990). The availability of choice has been identified as an important link to quality of life (Hughes, Hwang, Eisenman, & Killian, 1995; Stancliffe & Parmeter, in press). Until approximately 20 years ago choice was not an issue for people with mental retardation (Houghton, Bronicki, & Guess, 1987; Lancioni, O'Reilly, & Emerson, 1996). Prior to this time they were not given choices, rather staff members were charged with making decisions in the individuals' best interest. Lancioni, et al. (1996) provided a review of research regarding the issue of choice for people with severe and profound developmental disabilities. The review led them to make three conclusions: (1) most people with developmental disabilities seem to be able to make choices and express preferences at some level; (2) providing choices within individuals' daily lives is still a rather new and limited experience; and (3) the benefits of individual choice making need to be assessed further.

There is evidence that the opportunity for choice is correlated with adaptive behavior and level of mental retardation (Schalock, 1994; Stancliffe & Abery, 1997; Stancliffe & Wehmeyer, 1995; Wehmeyer & Metzler, 1995). The greater the severity of mental retardation the less opportunity there tends to be with regards to choice. The lives of people with severe mental retardation tend to be subject to greater programming, uniformity, and restrictions (Stancliffe & Abery, 1997). Therefore, when assessing choices available for people with severe mental retardation, Stancliffe and Abery (1997) suggested assessing choice in every day activities such as clothing, meals, or bedtime.

A definition of empowerment, that specifically refers to people with disabilities, states that "empowerment refers to the capacity of disenfranchised persons to understand and become active participants in matters that affect their lives" (Bolton & Brookings, 1996, p. 256). Thus, the ability and opportunity to make choices is important to the lives of people with mental retardation. This ability and opportunity is compatible with the ideas presented in the rehabilitation and normalization philosophies.

To this end, despite the fact that service programs have attempted to eradicate segregation of people with mental retardation, lack of participation in an integrated social environment is not necessarily bad if the individual is in the segregated environment by informed and active choice (Bullock & Mahon, 1992). Thus, choice is an essential component to the experience of community inclusion in that community inclusion requires the ability and opportunity for choice.

Support

In both research literature and agencies services there has been an emphasis on the importance of the provision of support. There are three key methods of providing support for people with mental retardation: (a) paid support, which is typically referred to as supported living or supported employment and is performed by a person who is a paid disability service provider and who provides assistance, feedback, companionship, or contact to assist a person with a disability participate in a work or community setting; (b) natural support, which is provided by someone who is not a paid disability service provider and who provides assistance, feedback, companionship, or contact to assist a person with a disability to participate in a work or community setting (Storey & Certo, 1996); and (c) peer support which is someone who also has a developmental disability who provides support in the form of assistance, feedback, friendship, or advocacy.

Quality of Life

As previously stated, there is a growing recognition that inherent in the development of all rehabilitation programs is the goal of improving quality of life (qol) for the consumers that are being served by the program (Condeluci & Williams, 1997; Halpern, 1994). Thus, there has been increased attention given to the construct of quality of life and also the desire to measure it (Fabian, 1991). Supporting this, Landesman (1986) believes that it is important to define quality of life in order to construct innovative programs that will achieve the desired quality of life outcomes. Despite attempts, researchers have identified problems with the use of quality of life assessments including: a) ambiguity in definitions of the construct; b) difficulty in constructing an instrument to measure the construct; and c) lack of understanding of how to use responses to improve quality of life for the population of people with disabilities.

There are varied definitions of quality of life. Fabian (1991) identified three broad approaches, all of which are used as approaches to measure quality of life outcomes. The first measurement approach considers quality of life as ratings of adaptive functioning. Adaptive functioning often has been used as an indicator of quality of life when an individual cannot respond by self-report either due to lack or limited physical or cognitive ability. Baroff (1986) asserts that quality of life is theoretically related to adaptive functioning with the argument that the greater amount of integration in the community the higher the level of competency in various environments and the higher one's quality of life will be. Fabian (1991) has identified some problems with adaptive functioning as an indicator of quality of life: a) there is a lack of empirical research to support the relationship between adaptive functioning and quality of life; b) if one believes that quality of life is at least in part subjective, then this form of measurement is insufficient; and c) there is controversy regarding appropriate criteria (e.g., deficits versus strengths) for measuring adaptive functioning. Although adaptive functioning is a promising addition to quality of life assessments, there remain unresolved issues regarding the appropriate criterion behaviors, the mixture of satisfaction scales with adjustment scales and the nature of the relationship between subjective well-being and adaptive functioning (Fabian, 1991).

The second approach to measurement of quality of life is using social indicators to measure changes in response to services and programs provided. Social indicators are defined as objective measures of quality of life because they include data such as unemployment rates, medical history, and socioeconomic status. Social indicators as a means of measuring quality of life may be useful in rehabilitation program evaluation. Such indicators provide a measurable change in quality of life of the individuals targeted, given participation in a specific program. But this form of measurement does not take into consideration the importance of the indicator to the individual.

The third approach is to consider quality of life as a subjective experience, typically by self-reported level of life satisfaction across multiple domains including transportation, vocational/employment, housing, education, spiritual fulfillment and leisure/recreation (Halpern, 1994). Taylor and Bogdan (1996) state that quality of life is a subjective experience. People experience the same circumstances differently. What enhances the quality of life of one person, may detract from another. Thus, some feel that quality of life should be evaluated in terms of personal values and needs (Flanagan, 1978; Parmeter, 1992). This assumes that the individual respondent is able to express satisfaction across domains and that the individual's prior life experiences are sufficient for deriving a standard for the current conditions. Self-reports of life satisfaction require that respondents have the ability to form judgments. This has typically been a source of contention when the respondents are individuals with developmental disabilities, specifically mental retardation.

Halpern (1994), in defining quality of life identified fifteen outcomes that are associated with three domains. These three domains include: (a) physical and material well-being; (b) performance of adult roles; and (c) personal fulfillment. The first domain, physical and material well-being has four basic outcomes including: (a) physical and mental health, (b) food, clothing and lodging; (c) safety from harm; and (d) financial security.

These are also compatible with Maslow's basic needs. The second domain, performance of adult roles includes the following outcomes: (a) mobility and community access; (b) vocation, career, employment; (c) leisure and recreation; (d) personal relationships and social networks; (e) educational attainment; (f) spiritual fulfillment; (g) citizenship; and (h) social responsibility. Halpern (1994) states that these outcomes also describe community integration, community adjustment, and independent living. The third domain, personal fulfillment, includes the three outcomes of (a) happiness, (b) satisfaction, and (c) a sense of general well-being.

Fabian (1992) noted that the choice of method of measurement and subsequent instrument should depend on the nature of the disability and the purpose for which the approach to assessing quality of life is intended. There is evidence that circumstances in one's life and subjective evaluation of circumstances may be independent, reflecting the complexity of the manner in which individuals find meaning in their experiences and underscore the importance of subjective outcomes.

Assessing Quality of Life

Hughes and Hwang (1996) suggest that there are two sets of variables that influence quality of life: person variables and environmental variables. Person variables include demographics such as age, marital status, income, severity of disability, level of support needed, and community adjustment. Environmental variables include work conditions, living conditions, residential opportunities, and availability of services and support.

Felce and Perry (1996) suggest a similar but more comprehensive model of quality of life that includes objective life conditions, subjective well being, and personal values and aspirations. Objective life conditions are the person and environment variables defined by Hughes and Hwang (1996). Subjective well being is defined as the level of satisfaction with each of the indicators in the life condition. Personal values and aspirations capture the importance of objective life conditions to the individual. In other words, a comparison of measures of current life situation, subjective satisfaction, and personal values and aspirations identifies the "goodness of fit."

Harner and Heal (1993) assessed the psychometric properties of the Multifaceted Lifestyle Satisfaction Scale (MLSS) which looks at the following domains: living arrangements and communities, personal relationships, recreation and leisure, employment, and degree of self-direction. They found that the MLSS appears to be reliable and valid for assessing subjective life satisfaction in the areas of living arrangement, friendships, recreation, employment, and self-direction. The specific subscales used in this research were: (a) community satisfaction, (b) friends and free time satisfaction, (c) job satisfaction, (d) recreation and leisure satisfaction, (e) satisfaction with services, and (f) satisfaction with interpersonal interactions. The MLSS was developed to address the need for a reliable and valid scale to assess life satisfaction for people with mental retardation within various life domains. In their review of literature, Harner and Heal (1993) identified several factors associated with successful placement in community settings, including: sense of belonging, personal benefactors, social networks, employment, social behavior and skills, and support services.

The Consumer Satisfaction Survey (Temple University, 1988 as cited in Sands & Kozleski, 1994) was designed to evaluate the constructs consumer satisfaction and quality of life for people with developmental disabilities. The constructs are examined by responses to items in the following areas: (a) services received, (b) satisfaction with services, (c) independence/interdependence, (d) community activities, (e) productivity, and (f) needs for supports, services, and assistance (Sands & Kozleski, 1994). Using this survey, Sands and Kozleski (1994) compared quality of life of people with and without developmental disabilities and found differences on several dimensions. For example, adults with disabilities were less likely to be married, and more likely to lack stable intimate partners. Also, people with disabilities rated themselves as having low to moderate independence. More importantly, people with disabilities reported less opportunity to make choices.

The Quality of Life (QOL) Interview (Lehman, 1988 as cited in Fabian, 1992) is a structured interview which assesses an individual's life experiences across eight life domains including: living situation, family social relations. leisure activities, physical and mental health, safety, finances, and work/nonwork. This protocol was specifically prepared and assessed with people with severe mental illness. The interview elicits both objective and subjective data in each of the life domains. Reliability coefficients for people with severe mental illness ranged from .79 for global life satisfaction to .88 for satisfaction with living situation. The test-retest reliability ranged from .41 for satisfaction with safety to .95 for satisfaction with work (Fabian, 1992).

Summary

This study was informed by knowledge generated in the fields of mental retardation, rehabilitation, rehabilitation counseling, psychology and special education. The literature review substantiated the importance of community integration, social role, support, and choice in studying the phenomenon of community inclusion. A study such as this was necessary to begin to define and measure community inclusion with a more holistic and psychosocial nature rather than the typically used definitions that define community inclusion as merely a measure physical presence in the community.

Chapter III

METHODOLOGY

The purpose of this study was to operationalize community inclusion and understand the experience for people with mental retardation. Community inclusion was operationalized using measures of community integration, social role, social support, and choice. To examine the utility of this multi-dimensional measurement approach the reliability of the measures were examined. Cronbach alphas were used to examine the internal consistency of the measures. A correlation analysis of the relationship among the four components was also performed to better understand the contribution of each component to the comprehensive concept of community inclusion. The relationship between community inclusion and quality of life was also examined. Quality of life was measured using a subjective measure of life satisfaction and the objective measures of adaptive behavior and social indictors. To further explore the value of the measures the scores on each measure and the total of all measures were compared by agency program. The research questions are as follows:

(1) Are the measures for each of the components of community inclusion (community integration, social support, social role and choice) reliable?

(2) Is there a relationship between proposed components of community inclusion: community integration, social role, social support, and choice?

(3) Is there a relationship between community inclusion and quality of life?

(4) Is there a difference in scores on measures of community inclusion for people in different agency programs?

Specific hypotheses as well as measures used to evaluate each question are listed in Table 2.

Research Site

Clinton-Eaton-Ingham Community Mental Health Community Services for the Developmentally Disabled in mid-Michigan was the site of this study. Within this comprehensive mental health agency is the division of the agency that serves people with developmental disabilities, Community Services for the Developmentally Disabled herein known as CSDD. The mission of CSDD reflects a commitment to community inclusion. “The mission of CSDD is to promote and support ongoing choices and opportunities for people and their families to be full and equal citizens in the community” (K. Slater, personal communication, June 10, 1996).

During the early 1990s the agency conducted client satisfaction surveys. In these surveys, clients expressed that they were not satisfied with their sheltered workshop placements. The sheltered workshops were developed in the 1960s and 1970s as ways to train and prepare people with disabilities to work in the community. Unfortunately, they became permanent placements for many people, some of whom are still being served at the same workshops. The surveys showed there was a desire expressed to work, volunteer, and participate in recreation in community settings (R. Coelho, personal communication, April, 1996). This initiated change and evolved into the current agency structure that has a community inclusion focus. The various agency programs include: Vocational Services, Transitions North and South, and Transitions Central.

Vocational Services

The vocational services division of CSDD attempts to help consumers find and maintain paid employment. Typically, the employment is part-time with minimum wage pay. All consumers currently receiving vocational services within an employment setting continue to receive support from agency staff. The range of this support from agency staff is from one hour per month to six hours per day with the latter being offered on a short term basis. In providing support services, the possibility of fading by paid staff must be foreseeable. Fading is the gradual reduction of paid support as the consumer's ability to work independently and as natural supports (a person not paid) are developed within the work site (T. Knudtson, personal communication, June, 1998).

Transitions

There are two Transitions sites, North and South, that CSDD consumers may attend. Each Transitions site has two groupings. Transitions 1 is what would familiarly resembles a sheltered workshop setting in which consumers participate in pre-vocational skill development and paid piece-work. The programs provide community integration activities (i.e., trips to community locations), as well as other activities promoting inclusion (i.e., support groups, advocacy training) (Daniel DeVaney, personal communication, May, 1996). This research used the North and South Transitions 1 consumer lists. Transitions 2 is an Adult Daily Living (ADL) center. The consumers at Transitions 2 (the ADL center) have high personal care needs. The daily programs typically focus on teaching consumers daily living skills and providing personal care needs. Consumers within Transitions 2 the ADL center typically have limited communication skills and poor receptive language ability. Given these limitations no participants were sought from the Transitions 2 settings.

In 1993, CSDD accepted a grant from the Michigan Department of Mental Health to develop a community inclusion project called Transitions Central. An integral part of the Project's philosophy is that community inclusion be addressed through regular volunteer, leisure, education and employment activities. It was the belief of the Adult Day Service administrator (Daniel DeVaney, personal communication, May, 1996) that community integration and inclusion would become a reality if paid employment was not considered the only outcome. While the Project continues to actively promote the development of paid employment sites by the staff, there is also the opportunity for volunteer, leisure, and educational sites to be developed. It was also the belief that these unpaid experiences could be beneficial in developing the skills for paid employment. The success and satisfaction of the consumers in this project influenced the initiation of programmatic changes in Transitions North and South. The agency has focused on providing consumers in the Transitions programs the opportunity to experience a variety of community activities at volunteer, leisure and educational sites. One objective of these activities is to give consumers the opportunity to develop and express preferences.

Recruitment of Participants

The target population for this research are adults with mental retardation residing outside of the institutional setting (homes having less than 16 people in the residence) who are consumers of services at CSDD. Volunteers were recruited from two agency programs including Vocational Services and Transitions (sheltered workshops).

Program Lists

One list of participants from the Vocational Services Program was obtained. Two lists of participants from Transitions were obtained. Two names on the Vocational Services list that were from another program (SITS) were used to pilot the measures were eliminated from the list. The final Vocational Services list contained 141 names. Lists from Transitions North and South contained 92 and 84 names respectively. The combined three-list total was 315. There were 21 names that appeared on both the Vocational Services list and one of the Transitions lists. Upon removal of redundant names, there were then 294 possible participants.

Initially, there was a target number of fifty participants from each list to get an appropriate sample size. CSDD staff anticipated that there would be a high consent rate. Therefore it was not deemed necessary to contact all individuals on each list. Rather, each list was numbered and sixty people from each list were randomly selected using a random number chart (Hopkins and Glass, 1978). Despite an initial mailing to these 180 randomly selected people, it should be noted that eventually all of the consumers or guardians on each list were contacted to consent to participate. The following is a list of results of contacts.

1. There were 126 consumers that consented to participate in the interview process.
2. There were eight names on the Vocational Services list that were later determined to be closed cases.
3. The whereabouts of four people on the list were unknown to agency staff.
4. There were six guardians who replied that they did not want the consumer to participate.
5. There were seven guardians who could not be contacted due to inaccurate addresses.
6. One individual had recently been transferred to a nursing home and could not be contacted.
7. One individual had retired and was no longer involved in services.
8. Ten consumers stated to CSDD staff that they had no interest in participating.

9. One consumer agreed to participate but his mother refused to allow him to talk on the phone to schedule an appointment.
10. Sixteen consumers did not respond to CSDD staff contact.
11. There was no reply from 114 guardians contacted by mail.

Consent Procedures

Some consumers maintain their own guardianship and others have legal guardians. Of the 294 possible participants, 88 consumers were listed as their own guardians while 206 had legal guardians that included parents, siblings, community advocates and lawyers. All procedures approved by the CEI/CMH Board and Michigan State University University Committees on Research Involving Human Subjects (UCRIHS) were followed. Consent for participation was solicited in three manners.

First, guardians were mailed an envelope containing: (a) a letter from the CSDD program evaluator overseeing this research, Richard Coelho, (b) a letter from the researcher introducing the purpose of the research, (c) the consent form for the guardian to sign and return, and (d) a self-addressed stamped envelope addressed to Richard Coelho (See Appendix A).

Second, if the consumer did not have a guardian or if the guardian provided consent then consent was sought from the consumer. A CSDD staff member was asked to approach each consumer to introduce the project by reading the Community Inclusion Research-Volunteer Protocol and the Community Inclusion Informed Consent Form. Every consumer who volunteered was the asked to provide consent to the CSDD staff by signing the Consumer Consent Form (See Appendix B).

Finally, the interviewer, prior to the actual administration of the measure, again explained the purpose of the research. Each consumer again signed an Introduction and Consent Form (See Appendix C). After this form was signed the interview began.

There were several guardians and consumers who requested further information regarding the research or the measures to be used. An agency administrator and/or the researcher verbally provided this information when requested. There was no follow-up contact made with either guardians or consumers that did not respond. This was in agreement with guidelines established with the host agency, CSDD, as well as the University Committee on Research of Human Subjects prior to beginning the research process.

Instrumentation

Research instruments were needed to measure both community inclusion and quality of life. To determine the options with regard to instrumentation, a search for appropriate measures was undertaken. This search included an examination of previously published studies within the fields of mental retardation, rehabilitation, rehabilitation counseling, psychology and special education. It also included a search of the internet and several projects that have published information in such a format. The results of these searches and subsequent decisions regarding measures are discussed in the following sections.

Community Inclusion

There were no research instruments located that measure community inclusion by focusing on the specific components identified by this researcher. Therefore a review of literature was conducted to find instruments or questions to appropriately measure the components of community inclusion: (a) community integration, (b) social role, (c) support, and (d) choice.

Community Integration

The purpose of a measure of community integration is to determine the physical presence in the community during the past month (30 days) in typical community settings. Community integration was measured using the Community Activity and Participation Checklist.

While it is very similar to the measures used by Stancliffe and Hayden (1998) (Variety of Community Places Used and Social Activities in the Last 30 days) and Sands and Kozleski (1994) (Participation in Community Activities and Recreation and Leisure Activities sections on the Community Satisfaction Survey), it has been altered to fit the community in which the participants live and settings in which they have access. The measure used in this study, the Community Activity and Participation Checklist (Appendix D), was completed during the interview by asking the consumer is this was an activity recently participated in or a community location recently visited. Items 24 and 25 asked the individual if there was any other activity not mentioned that they had participated. If the individual had partaken in this activity a score of 1 would be assigned. If there was no participation then a score of zero was assigned. All responses on this checklist were totaled to provide a range of scores between 0 and 25 to create one Community Integration score. The higher the score the more the individual participates in the listed community activities.

Table 2

Hypotheses and Measures to Evaluate the Research Questions

Hypotheses	MEASURES
Hypothesis for Research Question 1:	
The measures for each of the four components of community inclusion (community integration, social support, social role and choice) will be internally consistent.	1. Community Activity and Participation Checklist 2. Social Role Checklist 3. Social Supports Self Report 4. Choice Questionnaire
Hypothesis for Research Question 2:	
There will be a statistically significant positive relationship between proposed components of community inclusion: community integration, social role, social support, and choice.	1. Community Activity and Participation Checklist 2. Social Role Checklist 3. Social Supports Self Report 4. Choice Questionnaire
Hypothesis for Research Question 3:	
There will be a statistically significant positive relationship between community inclusion and quality of life.	1. Community Inclusion Total Score 2. Community Activity and Participation Checklist 3. Social Role Checklist 4. Social Supports Self Report 5. Choice Questionnaire 6. Consumer Satisfaction Survey 7. ICAP score 8. Consumer-Agency Data: a. Vocational/Day Program b. Residence c. Level of Paid Support d. Health Status e. Income f. Use of Physical Aids g. Behavior program usage

Table 2 cont'd

Hypothesis for Research Question 4: Participants from Vocational Services will have statistically significant higher scores on measures of community inclusion than participants from Transitions.	1. Community Inclusion Total Score 2. Community Activity and Participation Checklist 3. Social Role Checklist 4. Social Supports Self Report 5. Choice Questionnaire 6. ICAP score 7. Consumer-Agency Data: a. Vocational/Day Program b. Type of Residence c. Level of Paid Support d. Receptive Communication e. Expressive Communication f. Health Status g. Income h. Use of Physical Aids i. Behavior program usage

Social Role. No appropriate measure or model was found in which the individual's social role could be measured. Therefore, social role was measured using the Social Role Checklist (SRC) which was created for this study. This instrument (See Appendix E) asked the participant if he/she performs a variety of common social roles (e.g., friend, church member, club member, significant other, or parent). The SRC is a list of common roles people hold in the community and the individual responded "yes" or "no" to whether they performed such a role. Each "yes " response received a score of "1". A response of "no" or "don't know" received a score of "0" indicating that, from the participant's perspective, this is not a role that the individual holds. At the end of the checklist the individual was asked if there are any other roles that the individual has in the community. The interviewer recorded all responses. For each response determined by the researcher as a valid community role, a score of "1" was added.

If the response was to any role item was yes, a follow-up question was posed to find out more information about the role and the responsibilities of the role. A summary of this response was recorded. The purpose of the follow-up was to gain additional insight into the roles that people with mental retardation hold in the community and to reduce the possible response bias of acquiescence. The follow-up responses often added to the understanding of the roles and the meaning in the life of the individual. A single total score was calculated. The higher the total, the greater number of community roles the individual is presumed to hold.

Social Support. For this study, level of support was determined using an adapted version of the Social Supports Self-Report (SSSR) (Lunsky & Benson, 1997) (Appendix F) which evaluated the experience of support. The SSSR (Lunsky & Benson, 1997) was adapted from Reiss-Peterson Social Support Self-Report (Reiss & Benson, 1985). The SSSR is a two-part instrument. Slight changes were made to the language of the questionnaire to meet the needs of the sample .

First, following the established protocol, the interviewer elicited the identity of people in the lives of the participant. The questions covered four sources: family, friends, romantic partners, and staff. After gaining a list of potentially supportive people, the participant was asked to evaluate the quality of the support provided by each source. The quality of support was determined by asking five questions for each identified person. These questions are: 1) How often do you see or talk to ____________? (TALK) 2) How often do you talk to ________ about your feelings? (FEEL) 3) How much do you like ____________? (LIKE) 4) How much does _________ help you with your problems? (PROBLEMS) and 5) How much do you help ___________ with his/her problems? (RECIPROCITY)

The response choices and assigned values are: "A lot" a score of "3" , "Some" a score of "2", and "Not at all" a score of "1" . A score of "0" was assigned if there was no such person in the individual's life indicating no support available from such person. The scores were examined using the total related to each identified person and the reported level of support.

Choice. Choice was measured using 10 items selected from the Choice Questionnaire (Appendix G) (Stancliffe & Abery, 1997). The questions are specific regarding everyday choices about domestic matters (bed time, cleaning, eating, telephone use, and owning a pet), staff, money and spending, social activities, community access, personal relationships, work/day activities, and overall choice. While this scale provides the option of being completed by a knowledgeable proxy (Stancliffe & Abery, 1997), in this study the questionnaire was completed the questionnaire during the interview process. For this self-report, the interviewer selects the appropriate score after eliciting information during the interview through questions and subsequent probes. There are three possible scores for each item. A score of "3" means that the person reports making the choice actively, independently and without restrictions all or almost all of the time. A score of "2" means that the person reports making the choice sometimes, and also usually needs help in making the choice. A score of "1" means that the person reports that others make such decisions.

Stancliffe and Abery (1997) reported very satisfactory reliability for the Choice Questionnaire in a study of people with intellectual impairment. Consistency coefficients were .81 for self-reports and .90 for staff responses. Test-retest correlation was .77 for the item by item agreement on self-report and .85 on staff report with the total score. The test-retest correlation was .95 for total score correlation on self-report and .89 on staff report. The mean interrater agreement was 91.9% using 33% of the sample. Content validity was evaluated by expert review and the questionnaire was judged to be relevant and comprehensive. Concurrent validity was established by correlating total scores on the Choice Questionnaire with the Empowerment/Independence scores from the Quality of Life Questionnaire (Schalock, & Keith, 1993) resulting in a correlation coefficient of .79 for self-report data and .83 for staff reports. To assess the Choice Questionnaire's construct validity, a test of the ability to discriminate between participant's living semi-independently or in group homes was performed. The t-test yielded a significant difference in the expected direction in both the self-report data t(24)=4.26, p=.001, and staff reports t(37.8)=5.3, p<.00005.

Quality of Life

The definition and measurement of quality of life (QOL) has been controversial, specifically when considering the population of people with developmental disabilities (Day & Alon, 1993). Primarily the debate discusses whether QOL should be measured subjectively or objectively.

Subject measures of quality of life typically looks at life satisfaction (Day & Alon, 1993; Fabian, 1990; Schalock, 1990; Schalock, 1994; Taylor & Bogdan, 1990; Taylor & Bogdan, 1996). Self-reports of life satisfaction require that respondents have the ability to form judgments. This may be difficult to accomplish when the respondents are individuals with developmental disabilities, specifically mental retardation.

The objective measures of QOL particularly for people with mental retardation are typically adaptive functioning and/or social indicators (Day & Alon, 1993; Fabian, 1991; Felce & Perry; 1995; Harner & Heal, 1993). Fabian (1991) identified several problems with using adaptive functioning as the indicator of quality of life. There is a lack of empirical research to support the relationship between adaptive functioning and quality of life. Using adaptive behavior as a single measure eliminates any subjective assessment of QOL. Also, there is some controversy regarding the appropriate means of measuring adaptive functioning (e.g., deficits versus strengths). Social indicators are defined as objective measures of quality of life because they include data such as unemployment rates, medical history, and socioeconomic status. Such indicators provide a measurable change in quality of life of the individuals targeted, given participation in a specific program, but this form of measurement does not take into consideration the importance of the indicator to the individual.

Given the contention with the various measures, it has been suggested that QOL be measured both subjectively and objectively with the population of people with mental retardation given (Fabian, 1990; Halpern, 1994; Taylor & Bogdan, 1990; Taylor & Bogdan, 1996). In an attempt to measure QOL as thorough and accurately as possible, this study used both subjective and objective measures of quality of life. As for subjectively evaluating quality of life, previous research provided several articles with a variety of instruments measuring life satisfaction. After an examination of several instruments, it was determined that it would be best to develop an instrument that would meet the needs of this specific population while evaluating the construct in a manner consistent with the study. Objective quality of life was measured using adaptive behavior scores and social indicators.

Subjective Quality of Life

Most people agree that quality of life is primarily a subjective concept (Borthwick-Duffy, 1997) often referred to as life satisfaction. Life satisfaction can be measured in various ways, for example, it can be measured through open-ended questions that ask for an individual's point of view. It can also be measured by asking for evaluations to more closed ended questions such as asking for a rating (e.g., using a likert scale). Finally, life satisfaction has also been described as "goodness of fit." This is defined as the fit between the individual's current life situation and the desires or goals of the individual (Felce and Perry, 1996). While there are many instruments available for use in measuring quality of life, and more specifically life satisfaction, these measures did not fit the need of this research. Typically measures were either too long or used language that was beyond the comprehension level of the target population. The measure that was developed for this study was specifically designed to meet the objectives of this study which are to be succinct and comprehensible while also identifying levels of satisfaction on the part of the participant. Previously established instruments were used, however, to help develop the content of the instrument used for this study.

The measure of subjective QOL (life satisfaction) was the Consumer Satisfaction Survey (Appendix H). The goal was to ask the consumer both their satisfaction and preference with regard to the life domains of: (a) housing, (b) employment, (c) leisure, (d) friendships, and (e) overall life satisfaction. For each domain, the participant was asked if they feel happy, okay or unhappy about the current situation. There was a corresponding scale that accompanied the three choices used to assist the consumer in responding. In an attempt to increase the reliability of the responses, the order of choices was varied. That is, the choices "happy," "okay, " and "unhappy" were presented in different order for each question.

The scoring was "1" for a response of unhappy, "2" for a response of okay, and "3" for a response of happy. The scores from each domain were totaled to one score. Additionally, consumers were asked follow-up questions in each domain to validate the responses. The follow-up questions asked participants to identify a preferred situation. The questions regarding how the participant feels about their life in general were asked at both the beginning and end of the interview to increase reliability.

Objective Quality of Life

Adaptive Behavior. Adaptive behavior was measured on the Inventory for Client and Agency Planning (ICAP) (Bruinicks, Hill, Weatherman, & Woodcock, 1986) CSDD staff completed the ICAP for all individuals receiving residential services from the agency and this is located in the client case file. The ICAP assesses adaptive and challenging behavior. Adaptive behavior is measured on four domains: (a) social and communication, (b) personal living, (c) community living, and (d) motor. Maladaptive behavior is measured as (a) internalized, (b) externalized, and (c) asocial. There is an overall 2-total total score that is converted into a 1-digit service level score. For example, a person receiving a total score of 55 has a service level score of 5, or a person receiving a total score of 68 receives a service level score of 6. The service levels range from 1 to 9. Persons at level 1 require total care and supervision, at level 5 require regular care and close supervision, at level 7 require some care and supervision, and at level 9 require infrequent care or supervision. The test-retest and interrater reliability for each domain ranges from .8 to .9 (Bruinicks, Bradley, Hill, Weatherman, & Woodcock, 1986; Bruinicks, Woodcock, Hill, & Weatherman, 1985).

The ICAP report was located in the consumer case file. Both the weighted average score (1-99) and the service level score (1-9) for the ICAP were recorded on a demographic sheet for each consumer. The ICAP could also be used to provide the following basic demographic data: (a) gender, (b) date of birth, (c) primary and secondary disability information, and (d) level of mental retardation. These data were transferred to a data information sheet (see Appendix I).

Social Indicators. These were collected on the demographics sheet (see Appendix I, items D, E, H, I, J, K, L, and M) that asked for information suggested by other researchers (Schalock, 1994). The specific data used as social indicators were: current residential setting, work or day activity setting, level of paid support, health status, income level, communication level, use of physical aids, and use of a behavioral treatment plan.

Procedures

Design

The purpose of this study was to define community inclusion as well as expand our understanding of the experience for people with mental retardation from a community mental health program. After several meetings with agency administrators and staff, an application to conduct research was approved by Clinton-Eaton-Ingham (CEI)-Community Mental Health (CMH)-Community Services for the Developmentally Disabled (CSDD).

Data Collection

Consent procedures. Of the approximately 800 consumers at CSDD, there were 294 who were appropriate for participation in this study. This means that the individual was capable of comprehending and communicating in a manner applicable to the survey items. Initially this was determined by the individual's agency placement. Of the consumers appropriate for the study, some consumers had guardians in the community who were typically family members, attorneys, or advocates from the community. Prior to data collection, consent was obtained from all guardians. Envelopes were prepared with a CSDD transmittal letter, a researcher transmittal letter explaining the study, a consent form for the guardian to sign and return, and a self-addressed stamped envelope. Once the guardian consent has been received then consent from the consumers with guardians can be sought.

As for consumers who maintain their own guardianship, and consumers who have guardian consent, agency staff delivered, and read if necessary, the consumer consent form. The staff then obtained informed consent from all volunteers to participate. All volunteers that consented to participate in the study were interviewed.

It is important to note that both the consent letter guardians and the consent form for consumers stated that once the interview process was completed, the consumer would be paid five dollars. While this was an incentive for some consumers to participate, the intention was to compensate the participant for the time spent completing the interview.

Interview Procedures. Individual interviews were set up once consumer consent was received. At the interview, the researcher provided an introduction to the study and then sought consent for participation in the study. The researcher then asked for verbal consent to participation. Once informed consent was obtained, the researcher administered the measures: (a) Community Usage Checklist, (b) Social Role Checklist, (c) Social Supports Self Report, (d) Choice Questionnaire, and (e) Consumer Satisfaction Survey. Once was been completed the researcher thanked the participant for their participation and asked if there were any questions. The participant was then paid five dollars.

Demographic data collection. Demographic data were obtained from consumer case files. If the case file was incomplete, case managers or other agency staff personnel were asked to provide such information. The information was recorded on separate demographic sheets.

Piloting the Interview. While most of the scales used in this research were either previously used in other research or were variations of scales used in other research, the interview process including gaining consent, was piloted. The pilot participants were four CSDD consumers recruited from the Supported Independent Transition Services (SITS) program. CSDD staff reported that consumers in the SITS program would not be on the lists from the sample population.

Prior to the actual interview the volunteers were briefly told the purpose of the research and the purpose of the pilot interview. The researcher asked the volunteers to comment whenever a question was not clear and also to comment if they felt that a break was needed. During the pilot interviews, the researcher watched the volunteers for signs of distraction or fatigue. Each interview was timed. After each pilot interview was completed the volunteer provided feedback regarding their experience with the interview. The researcher asked the following questions. 1) How did you feel about the interview?, 2) Were there any questions that you could not answer? 3) Were there any questions that you did not want to answer? 4) Do you think that this interview was too long? 5) Is there anything about community inclusion that you think that I should have asked? 6) Do you think that $5.00 is a fair amount to pay someone for participating?

The pilot volunteer responses to the above questions were positive overall. There were no questions identified that the volunteer did not want to answer. Three of the volunteers reported some difficulty in choosing between response options "a lot" and "sometimes" and between "sometimes" and "never." on the Social Support Self-Report items. While this was noted, the volunteers did say that they were eventually able to make a choice. There were also comments that the open-ended questions regarding life satisfaction were difficult to answer. It is typical for many people with mental retardation to have difficulty answering open-ended questions (Sigelman, et al., 1983). No interview lasted longer than 25 minutes, which was within the timeframe set by the researcher. The volunteers indicated that the length of the interview was reasonable.

Each consumer was paid ten dollars for completing the interview and responding to the follow-up questions. The reason these volunteers were paid ten dollars rather than five was because it required a longer time commitment given the follow-up information solicited.

One agency case-worker consulted with the researcher to learn more about the purpose of the research interview and measures. Prior to the interview she provided feedback regarding the interview protocol including the type and phrasing of questions. She then voluntarily sat in on the interview to assure that questions and responses were providing the information that the researcher was looking to attain.

Changes were made to the interview protocol process as a result of the piloting experience and feedback. These changes were primarily in the wording of questions and the format of the measures to increase participant understanding and to also make data collection and analysis easier. One example involves the Community Activity and Participation Checklist. On the pilot interview there were 40 items. Eight of these items were "Other" responses. These were reduced to two "Other" items. Also, "Church Service" and "Church Social" were combined to make one item. The items "Civic Organization" and "Social Group" were eliminated because the pilot participants were not familiar with the meaning of each. Two examples of changes to facilitate analyses were in the scoring on the Social Support Self-Report and the Consumer Satisfaction Survey. In each case, the scoring was reversed so that the higher the score the greater the support or satisfaction. This was done to create compatibility with the score of other measures.

Data Collection

Interviews. Data for this study was collected from November, 1998 through December, 1998. The researcher, using the Community Inclusion and Life Satisfaction Survey as a protocol for the order and asking of questions conducted individual interviews. An introduction to the study was provided to the consumer who had previously consented to participate to agency staff. After being introduced to the study, participants were asked to sign a consent form (see Appendix K) in front of the researcher prior to the actual administration of the survey.

The interviews took place in various locations at the convenience of the participant. While there was always an attempt to secure a private location, this was not always possible. Some interviews were held in the individual's family home. Although parents, spouses, or roommates indicated that they would leave the room to provide privacy, there was often the indication that eavesdropping had occurred when they provided additional information to questions after the interview was completed. Some parents would not offer to provide privacy. If the parent wanted to stay in the interview area the participant was given the option of completing the interview at another time and place, usually at the work location. No participant indicated a desire to do so. In one interview at a group home, a staff member stated that it would be necessary for a staff person to be present. The option was given to the participant to conduct the interview at another time and in another setting. The participant consented to go on with the interview and given the dissatisfaction that the individual openly expressed about the home, the researcher determined that the presence of the staff had not suppressed responses. Other interviews were conducted at work site locations. These locations typically provided for greater privacy, although two participants selected to be interviewed in work break rooms that did have some co-worker traffic. Private interview rooms were provided at CSDD sites (Transitions North and South) and at another local vocational center. For two interviews it was necessary to include agency staff to assist in communication. These participants were asked if they wanted to complete the interview with the assistance of staff and both agreed.

After the completion of the interview, each participant was thanked and given five dollars.

Case File Data. After a consumer interview was completed, data were gathered from agency case files. This information was obtained from the CSDD file room by the researcher and recorded on the individual survey forms.

Staff Data. If there was demographic data that could not be obtained from the case file, a CSDD staff member was asked to provide such information. The most frequently asked question of staff was to provide the number of hours of staff paid support per week the participant received. This was often reported to be difficult to determine, so staff members were asked to estimate the number of paid support hours.

After the data collection was completed, data entry and analysis were completed using the SPSS Base 9.0 Grad Pack.

Data Analysis

Descriptive statistics were computed on the sample characteristics from the data collected on the demographic survey. Frequencies for the following categorical variables were computed: gender, residential setting, day activity setting, health, income level, receptive communication, expressive communication, and behavior treatment plan. Mean scores and standard deviations for the continuous variables age and adaptive behavior as well as for each of the community inclusion measures (Community Activity and Participation Checklist, Social Role Checklist, Social Supports Self-Report, and Choice Questionnaire) and the life satisfaction measure (Consumer Satisfaction Survey) were computed. Distributions of scores were examined for normality by computing scores of skewness and kurtosis. Skewness measures the symmetry of the distribution (SPSS, 1999). Normal distribution is symmetric, and has a skewness value of zero. A distribution with a significant positive skewness has a long right tail while a distribution with a significant negative skewness has a long left tail. A skewness value greater than 1 generally indicates a distribution that differs significantly from a normal distribution (SPSS, 1999). Kurtosis measures the peakedness of a distribution or the extent to which observations cluster around a central point (SPSS, 1999). For a normal distribution, the value of the kurtosis statistic is 0. Positive kurtosis indicates that the scores cluster more and have longer tails than scores in the normal distribution. Negative kurtosis indicates the observations cluster less and have shorter tails (SPSS, 1999).

To examine the reliability of the measures for each of the components of community inclusion (community integration, social support, social support and choice), the internal consistency of each measure of the four components of community inclusion was examined. The model of internal consistency, Cronbach's alpha, based on the average inter-item correlation was used to determine the internal consistency.

A Pearson correlation was used for this study to determine the relationship between the proposed components of community inclusion: community integration, social role, social support, and choice. Another Pearson correlation examined the relationship between community inclusion and subjective quality of life. This was done using the total score for community inclusion determined by the sum of scores on the four measures (community integration, social role, social support, and choice) and the measure of subjective quality of life (life satisfaction). A Pearson correlation also examined the relationship between the community inclusion score and adaptive behavior as measures on the ICAP. A minimum .05 level of significance was used a rejection level of statistical analyses.

Williams (1992) stated that a correlation "characterizes the existence of a relationship between variables." (p. 131) Correlation coefficients indicate the magnitude of the relationship between variables and the direction of the relationship (positive or negative) (Williams, 1992). A simple correlation indicates whether two or more variables vary together either positively or negatively but gives no indication of cause or effect (Williams, 1992).

Multiple regression analysis was used to examine the relationship between community inclusion and life satisfaction. The multiple regression method that was employed was the stepwise method. This procedure used subjective quality of life as the criterion variable and the four measures for the components of community inclusion as the predictors. Given the large variation in the numerical scoring of the measures, z scores were computed for each of the measures. A stepwise regression analyzed the relationship between community inclusion, the criterion variable, and social indicators, the predictor variables. There were eight predictor variables initially considered. These were residential setting, work/day activity program, level of paid support in home, level of paid support in school, health status, income level, use of physical aids, and use of behavior treatment plan. Given that each of these variables is categorical they were converted into dummy variables for the analysis.

Multiple regression is a technique used to determine a relationship between a criterion variable and the best combination or contribution of two or more predictor variables (Fraenkel & Wallen, 1993; Heppner, et al., 1992; Williams, 1992). The coefficient of the multiple regression (*R*) is similar to that of the Pearson correlation and indicates the magnitude of the relationship. The coefficient of determination is the square of the correlation and "indicates the variability among the criterion scores that can be attributed to differences in scores on the predictor variable" (Fraenkel & Wallen, 1993, p. 231). In the stepwise method, independent variables are entered into the analysis. The regression equation indicates the variables that are best predictors of the specified criterion (Heppner, et al., 1992). The first variable entered is the one that has the highest correlation with the criterion variable. The next variable is "the one that results in the largest increase in R^2. This is repeated until adding a variable does not result in a statistically significant increase in R^2. Thus, a stepwise regression identifies the variables that contribute the most unique variance in the equation and in what order." (Heppner, et al., 1992, p. 217-218).

Determining differences on demographic data between the two groups was an important preliminary step to address the differences in scores on measures between the participants in the two agency programs, Vocational Services and Transitions. True differences in the two groups needed to be verified. The mean scores for each group on each of the community inclusion measures (Community Activity and Participation Checklist, Social Role Checklist, Social Supports Self Report, and Choice Questionnaire) were computed. An independent samples t-test was used to determine significant differences between the scores of the two groups on the measures. A minimum .05 level of significance was used as a rejection level on these statistical analyses.

Chapter IV

RESULTS

Sample Characteristics

The sample in this study consisted of individuals who were consumers at the Clinton-Eaton-Ingham (CEI) Community Mental Health Board (CMHB) Community Services for the Developmentally Disabled (CSDD). Attempts were made to contact the 294 consumers who appeared on agency consumer lists. This yielded 126 consumers who consented to participate and completed interviews for a participation rate of 42.8%. A post hoc power analysis indicated that the sample of 126 consumers given a medium effect size (.15), and an alpha level of .05, would yield a level of power of .9453.

The total sample was composed of 64 (50.8%) males and 62 (49.2%) females. The age range for the sample spans a minimum of 22 years to a maximum of 86 years with a mean age of 42.91 years. The skewness of the distribution yielded a statistic of .660, which indicates normal distribution. The kurtosis analysis produced a statistic of .810 indicating the reported ages have longer tails than in the normal distribution. Given that these statistics are not greater than 1 or less than –1, normal distribution is assumed. A visual examination of the distribution of the ages of participants using a histogram indicated that there was an outlier, one participant was 86 years old with the next closest participant's age being 73. When the outlier was removed from the analysis the skewness statistic was lowered to .373 and the kurtosis statistic was also lowered to -.222, indicating a normal distribution.

The majority of the sample, 71 (56.3%) individuals, lived in a group home. There were 21(16.7%) individuals who were living independently, either alone or with a roommate or spouse. The other 34 (27%) individuals lived with families in private homes.

The hours for paid support varied among the majority of the sample in that most either received no support or total support. In terms of paid support at home, there were 45 (35.7%) individuals who received no paid support while 52 (41.3%) of the participants received over 100 hours of support in home per week. Of the remaining 30 individuals, 26 (20.6%) were receiving less than forty hours of paid support per week, three (2.4%) received 70 hours of support per week.

Two (1.6%) individuals reported being married and two (1.6%) reported being widows. All participants who are or have been married were consumers of Vocational Services. In terms of participant health, income, and communication, there was very little variation. For health status, there were 109 (86.5%) individuals in good health, with only three (2.4%) individuals in excellent health, eight (6.3%) in fair health, and six (4.8%) in poor health. There were only two (1.6%) of participants determined to have a moderate income, and all 124 (98.4%) other participants at low income.

There were 123 individuals who understood spoken language, one individual (.8%) utilized lip reading, and two (1.6%) utilized gestures or simple pictures to understand what was being communicated. To communicate, 90 (71.4%) individuals used sentences or phrases, 16 (12.7%) individuals used limited words, one (.8%) individual used structured sign language, six (4.8%) individuals used a communication board, and 13 (10.3%) individuals used gestures, noises, or pointing to symbols.

There were 64 (50.8%) participants who needed to use one or more physical aids (glasses, wheelchair, cane, hearing aid, etc), and 62 (49.2%) who needed no physical aids. There were 29 (23%) participants who have some type of behavior treatment plan and 97 (77%) who have none.

Participant adaptive behavior was measured using ICAP scores. There were 86 ICAP scores available and 40 missing. The majority of the missing scores were either for people living independently not actively receiving residential services or for people living in group homes contracted by CSDD to provide services (rather than a group home directly run by the agency). The scores available yielded a mean total score of 55.45 with a standard deviation of 14.2 or a mean service score of 5.5 and a standard deviation of 1.4. The ICAP skewness and kurtosis distribution statistics were -.203 and -.553 respectively. Given that these statistics fall between –2 and 2 normal distribution can be assumed. A visual examination of the scores using a histogram confirmed this assumption.

The participants in this study were consumers of at least one of the agency services, either Vocational Services or Transitions. There were 41 (32.5) participants from Vocational Services and 70 (55.6%) from Transitions. More specifically, 36 (28.6%) participants were from Transitions North and 34 (27%) from Transitions South. The participants from Transitions North and South are treated as one group given that the goals and activities of both settings are considered the same. In this sample there were 15 (11.9%) participants who were consumers of both Vocational Services and Transitions. A decision was made to group these 15 participants with the consumers who were listed as consumers of Vocational Services only. There were eighteen people who participated in the interview but did not complete the entire survey.

Demographic variables were examined by agency program (Vocational Services or Transitions) to determine significant differences between the two groups. Table 3 provides participant demographic information categorized by agency program. In comparing the characteristics of the two groups, Vocational Services and Transitions, both similarities and differences were found. Gender distribution was found to be similar between the groups. The Vocational Services group had 46.4% male and 53.6% female as compared to 54.3% male and 45.7% female in the Transitions group. Another similarity was in the use of physical aids. Approximately 50% of each group reported using some type of physical aid. Other similarities included health status, income and receptive communication, which as previously stated had little variation throughout the sample.

The mean age for participants in Vocational Services was significantly lower (40.2) than for Transitions (45.1) ($t=-.244$, $p<.01$). There were several categorical variables found to have statistically significant differences. These variables are residential setting, paid support in home, paid support in vocational/day program, expressive communication, and behavior plan use. A greater number of participants from Vocational Services lived in independent settings, while a greater number of participants from Transitions lived in group homes. Also, participants from Vocational Services received less paid support, had greater verbal communication, and used behavior plans less frequently than participants from the Transitions program

Community Inclusion Measures

There were four measures used as components of the Community Inclusion Score. These four measures were Community Activity and Participation Checklist (community integration), Social Role Checklist (social role), Social Supports Self-Report (social support), and Choice Questionnaire (choice). Table 4 presents the mean score and standard deviation for each measure. The total community inclusion score ranged from 25 to 187. The mean community inclusion score was 104.0 with a standard deviation of 31.96. All measures were reviewed for internal consistency (reliability). Table 5 presents the Cronbach's alphas for each measure of community inclusion. The alphas for the Community Activity and Participation Checklist (community integration) (.82), Social Supports Self-Report (social support) (.87), and Choice Questionnaire (choice) (.94) were adequate. The alpha for the Social Role Checklist (social role) (.57) is considered insufficient, although this alpha does not completely limit the utility of the measure (Heppner, et al., 1992).

Correlation of Measures

A Pearson correlation was performed using the four components, community integration, social role, social support, and choice. The Pearson correlation coefficient for each of the four components appears in Table 6. Cases were excluded pairwise, meaning that cases with missing values for one of the two variables were excluded. When tested for significance, the following pairs were found to have relationships with correlation coefficients significant at the less than .01 level: Community Integration and Social Role (.364), and Community Integration and Social Support (.367). The following pairs were found to have relationships with correlation coefficients significant at the less than .05 level: Community Integration and Choice (.251), Social Role and Choice (.205), and Social Role and Social Support (.196). There was no significant relationship found between Choice and Social Support.

Table 3

Participants Demographic Information Categorized by Agency Programs (n=126)

	Grouping		Test of Significance
	Voc Services	Transitions	
Gender			
Males	26 (46.4%)	38 (54.3%)	$\chi^2 = .768$
Females	30 (53.6%)	32 (45.7%)	DF = 1
Residential Setting			
Family Home	21 (37.5%)	13 (18.6%)	$\chi^2 = 41.7$***
Independent	20 (35.7%)	1 (1.4%)	DF = 2
Group Home	15 (26.8%)	56 (80.0%)	
Paid Support in Home			
No Paid Support	32 (57.1%)	13 (18.6%)	$\chi^2 = 41.4$***
11-40 Hours	15 (26.8%)	11 (15.7%)	DF = 4
41-80 Hours	3 (5.4%)	0 (0%)	
Over 100 Hours	6 (10.7%)	46 (65.7%)	
Paid Support in Voc/Day Program			
No Paid Support	29 (51.8%)	0 (0%)	
Less than 10 hours	3 (5.4%)	2 (2.9%)	$\chi^2 = 70.5$***
10-19 Hours	6 (10.7%)	4 (5.7%)	DF = 4
20-29 Hours	9 (16.1%)	3 (4.3%)	
30 or More Hours	9 (16.1%)	61 (87.1%)	
Health Status			
Excellent	1 (1.8%)	2 (2.8%)	$\chi^2 = 5.293$
Good	51 (91.1%)	58 (82.9%)	
Fair	4 (7.1%)	4 (5.7%)	DF= 3
Poor	0 (0%)	6 (8.6%)	

**p<.01
***P<.001

Table 3 cont'd

	Grouping		Test of Significance
	Voc Services	Transitions	
Uses Physical Aids			
Yes	31 (44.6%)	37 (52.9%)	$\chi^2 = .84$
No	31 (55.3%)	33 (47.1%)	DF= 1
Receptive Communication Understands:			
Spoken Language	56 (100.0%)	67 (95.7%)	$\chi^2 = 2.46$
Lip Reading/Written	0 (0%)	1 (1.4%)	DF= 2
Gestures/Pictures	0 (0%)	2 (2.9%)	
Expressive Communication			
Verbally-Sentence/Phrase	51 (91.1%)	39 (55.7%)	
Verbally -Limited Words	4 (7.1%)	12 (17.1%)	$\chi^2 = 24.34$***
Using Structured Signing	1 (1.8%)	0 (0%)	DF= 4
Using Symbol Board	0 (0%)	6 (8.6%)	
Using Gestures, Noises, Pictures	0 (0%)	13 (18.6%)	

**p<.01
***P<.001

Table 4

Sample Mean Score and Standard Deviations for Community Inclusion Measures

Measure	N	Means Score	SD
Community Inclusion Total	110	104.04	31.96
Community Activity and Participation Checklist	126	8.89	4.72
Social Role Checklist	124	3.0	1.72
Social Support Self-Report	109	71.0	26.4
Choice Questionnaire	120	20.69	7.71

Table 5

Cronbach's Alphas for Measures of Community Inclusion

Measure	N	Alpha
Community Activity and Participation Checklist	126	.8164
Social Role Checklist	124	.5725
Social Support Self-Report	109	.8729
Choice Questionnaire	120	.9392

Table 6

Correlation Coefficients for Measures of Community Inclusion

n=108

	Community Integration	Choice	Social Support	Social Role
Community Integration	1.00			
Choice	.251**	1.00		
Social Support	.367**	.115	1.00	
Social Role	.424**	.205*	.196*	1.00

* Correlation is significant at the 0.05 level (1 tailed)
** Correlation is significant at the 0.01 level (1tailed)

Scores on Measures by Agency Programs

There were four measures used as components of the Community Inclusion Score: Community Activity and Participation Checklist (community integration), Social Role Checklist (social role), Social Supports Self-Report (social support), and Choice Questionnaire (choice). Table 7 compares means scores on the measures by the two agency programs. T-tests yielded statistically significant differences for the measures of community integration, choice, and the total of all community inclusion measures. In each case the mean score for Vocational Services was higher than the means score for Transitions. While differences were not significant for social support (p=.058) and social role (p=.093), the p values require consideration before completely dismissing the differences.

Community Integration

Scores on the Community Activity and Participation Checklist ranged from 0 to 24. Overall, participant total scores on the Checklist yielded a mean score of 8.89 with a standard deviation of 4.72. Total scores yielded skewness and kurtosis statistics of .453 and .000 respectively. After a visual examination of the distribution using a histogram, a normal distribution is assumed.

Table 8 presents the percentage of "yes" and "no" responses to each of the items on the checklist categorized by Agency Vocational/Day Programs and the test of significance for each item. The community activities with the highest frequency were visits to a grocery store, department store, or fast food restaurant. The community locations that were least visited were a bar, hotel, or museum. The least participated in activities were visits to a bar, hotel, or museum, or participation in a league or team.

Activities that were named as "other" activities included work, bingo, fishing, collector's meetings, camping, library, vacation, walking, Special Olympics, hunting, visit a friend, joy rides in the car, golfing, arts and craft club, rollerblading, dances, bike riding, and dance class.

Social Role

Scores on the Social Role Checklist ranged from 0 to 8, with a mean score of 3 with a standard deviation of 1.72. The skewness statistics was .799 while the kurtosis statistic was .298. A visual examination of the scores using a histogram indicated that a one third (32.5%) of participants indicated holding two social roles. Despite this, there appears to be a normal distribution of scores. Table 9 indicates the frequency of "yes" and "no" responses for each of the social roles categorized by the agency program. The most frequently reported social roles were friend and church member. The least frequent social roles were parent and club member. The only apparent difference in roles between the two groups was in the role of volunteer. Seventeen (30.4%) people from Vocational Services reported being a volunteer while only nine (12.9%) from Transitions reported having such a role. There was only one role, church member, that participants from Transitions reported a higher percentage of the time.

Social Support

The Social Supports Self-Report had a range of 16 to 135. The mean total score was 71.25 with a standard deviation of 26.4. The skewness statistic of the distribution was .069. The kurtosis statistic of the distribution was -.433. Using these statistics, normal distribution can be assumed. A visual examination using a histogram supported this assumption. Table 10 indicates the total mean and standard deviation for each

Table 7

Comparison of Participant Mean Scores on Measures of Community Inclusion by Agency Program

	N	Mean	SD	Test of Significance
Community Activity and Participation Checklist				
Vocational Services	55	10.02	4.72	
Transitions	70	7.67	4.56	t=2.96**
Social Role Checklist				
Vocational Services	55	3.29	1.86	
Transitions	69	2.77	1.57	t=1.69
Social Support Self-Report				
Vocational Services	55	75.75	26.83	
Transitions	54	66.17	25.29	t=1.92
Choice Questionnaire				
Vocational Services	55	25.40	7.28	
Transitions	65	16.70	5.54	t=7.42***
Community Inclusion Total				
Vocational Services	55	114.60	30.19	
Transitions	53	93.44	30.36	t=3.67***
Consumer Satisfaction Survey				
Vocational Services	55	12.93	2.52	
Transitions	62	13.21	2.25	t=-.640

*p<.05
**p<.01
***p<.001

Table 8

Comparison of Frequency of "Yes" Responses for Items on the Community Activity and Participation Checklist by Agency Program

	Grouping	
	Voc Services (n=56)	Transitions (n=70)
	Frequency (%)	Frequency (%)
Grocery Store	43 (76.8%)	53 (75.7%)
Department Store	41 (73.2%)	50 (71.4%)
Movie Theater	18 (32.1%)	29 (41.4%)
Rented a Movie	31 (55.4%)	28 (40.0%)
Fast Food Restaurant	45 (80.4%)	53 (75.7%)
Sit Down Restaurant	41 (73.2%)	30 (42.9%)
Hotel	10 (17.9%)	7 (10.0%)
Exercise Facility	13 (23.2%)	15 (21.4%)
Park	25 (44.6%)	29 (41.4%)
Mall	38 (67.9%)	43 (61.4%)
Bar or Dance Club	8 (14.3%)	5 (7.1%)
Ice Cream Shop	23 (41.1%)	20 (28.6%)
Overnight at a Friends	19 (33.9%)	14 (20.0%)
Church or Synagogue	31 (55.4%)	44 (62.9%)
Volunteered	15 (26.8%)	18 (25.7%)
Bowling Alley	34 (60.7%)	36 (51.4%)

Table 8 (Cont'd)

	Grouping	
	Voc Services (n=56)	Transitions (n=70)
	Frequency (%)	Frequency (%)
Pool Hall	13 (23.2%)	9 (12.9%)
Museum	13 (23.2%)	1 (1.4%)
Concert, Play, or Musical	17 (30.4%)	10 (14.3%)
Participated in a League	12 (21.4%)	4 (5.7%)
Participated on a Team	10 (17.9%)	2 (2.9%)
Attended a Sporting Event	14 (25.0%)	11 (15.7%)
Support Group	11 (19.6%)	14 (20.0%)
Other	25 (44.6%)	9 (12.9%)
Other	11 (19.6%)	1 (1.4%)

Table 9

Comparison of Frequency of _"Yes" Responses for Items on the Social Role Checklist by Agency Program

	Grouping	
Item (Social Role)	Voc Services (n=55) Frequency (%)	Transitions (n=70) Frequency (%)
Someone's Friend	48 (85.7%)	61 (87.1%)
Church Member	30 (53.6%)	45 (64.3%)
Club Member	4 (7.1%)	3 (4.3%)
Advocacy Group	9 (16.1%)	3 (4.3%)
Support Group Member	17 (30.4%)	15 (21.4%)
Husband/Wife Boyfriend/Girlfriend	22 (39.3%)	27 (38.6%)
Parent	2 (3.6%)	1 (1.4%)
Helped Someone	26 (46.4%)	25 (35.7%)
Volunteer	17 (30.4%)	9 (12.9%)
Other Roles	4 (7.1%)	1 (1.4%)

Table 10

Comparison of Means Scores for Items on the Social Supports Self-Report by Agency Program

Item (Person)	Grouping Voc Services (n=55) Mean	 SD	 Transitions (n=54) Mean	 SD
Total Support	76.35	26.70	66.16	25.30
Spouse/Sweetheart	4.79	5.89	4.58	5.87
Mother	7.94	6.09	6.21	6.24
Father	6.5	6.14	4.56	5.56
Brothers	7.46	5.13	6.76	5.18
Sisters	6.89	5.77	7.26	5.56
Aunts	4.0	5.48	.91	2.66
Uncles	2.76	4.34	.83	2.43
Grandparents	2.54	4.32	.49	2.06
Roommates	4.02	5.34	5.11	5.71
Staff	7.52	5.93	11.09	4.03
Work Friends	7.33	5.43	8.06	5.43
Best Friend	8.96	5.48	8.15	6.42
Other	5.27	6.18	3.16	5.54

possible supportive person in the participants' life by agency program. The mean scores for almost all of the listed people are very close between the groups.

Choice

The scores on the Choice Questionnaire had a range of 10 to 36. The mean was 20.7 with a standard deviation of 7.7. The distribution skewness was .525 and the kurtosis was -1.086. While a normal distribution can be assumed using these statistics, a visual examination using a histogram highlighted the kurtosis score with the cluster of scores indicating reports of lower amount of choice.

Table 11 indicates the frequency of responses for each item by each agency program. For each item the reported level of choice was higher for participants from Vocational Services. The only item that over 50% of participants from Vocational Services reported making no choices was in determining how money is spent. On the other hand, participants from Transitions reported very few opportunities to make choices. The only item that less than 50% reported no choice being use of the telephone and that was primarily allowed after asking.

Quality of Life

Subjective Quality of Life

The mean score on the Consumer Satisfaction Survey was 13.08 with a range from 5 to 15, and a standard deviation of 2.37. A t-test between the score of the two agency groups indicated that there were no significant differences at the $p<.05$ level. Table 12 indicates the frequency of responses to questions regarding happiness with life situations. Table 13 indicates preferences regarding living, working, and friendship. The highest percentage of participants from both agency programs indicated that their

Table 11

Comparison of Frequency of Responses for Items on the Choice Questionnaire by Agency Program

Item	Grouping Voc Services (n=55) Frequency (%)	 Transitions (n=65) Frequency (%)
Bedtime		
I decide	32 (58.2%)	14 (21.5%)
I decide with help	0 (0.0%)	1 (1.6%)
Others Decide	23 (41.8%)	50 (76.9%)
Chores		
I decide	21 (38.2%)	8 (12.3%)
I decide with help	9 (16.4%)	2 (3.1%)
Others Decide	25 (45.5%)	55 (84.6%)
Drink or Eat		
When I want	38 (69.1%)	13 (20.0%)
If I ask	8 (14.5%)	15 (23.1%)
At set times	9 (16.4%)	37 (56.9%)
Telephone		
When I want	27 (49.1%)	9 (13.8%)
If I ask	19 (34.5%)	26 (40.0%)
Never or on schedule	9 (16.4%)	30 (46.2%)
Pet		
No restriction/I decide	25 (45.4%)	7 (10.8%)
I'd have to ask	14 (25.5%)	9 (13.8%)
Others Decide	16 (29.0%)	49 (75.4%)
House Alone		
No rules	32 (58.2%)	7 (10.8%)
Sometimes	7 (12.7%)	8 (12.3%)
Never	16 (29.1%)	50 (76.9%)

Table 11 Cont'd

Item	Voc Services (n=55) Frequency (%)	Transitions (n=65) Frequency (%)
Money		
I decide	12 (21.8%)	4 (6.2%)
I decide with help	13 (23.6%)	6 (9.2%)
Others Decide	30 (54.5%)	55 (84.6%)
Drink Beer or Wine		
I decide	28 (50.9%)	18 (27.7%)
I decide with help	11 (20.0%)	9 (13.8%)
Others Decide	16 (29.1%)	38 (58.5%)
Out Anywhere		
I can go anywhere	18 (32.7%)	5 (7.7%)
I ask	20 (36.4%)	9 (13.8%)
I am stopped or I go with someone	17 (30.9%)	51 (78.5%)
Home Late		
If I want	16 (29.1%)	3 (4.6%)
I decide with help	26 (47.3%)	12 (18.5%)
Others Decide	13 (23.6%)	50 (76.9%)
Off Work		
I decide	17 (30.9%)	3 (4.6%)
I decide with help	26 (47.3%)	15 (23.1%)
Others Decide	12 (21.8%)	47 (72.3%)
Overall		
Yes	20 (36.4%)	4 (6.2%)
Sometimes	20 (36.4%)	11 (16.9%)
Others Decide	15 (27.2%)	50 (76.9%)

Grouping spans both frequency columns.

preference for living and working would be to remain were they currently were. One striking difference found was that 20% participants from Vocation Services indicated that they would rather live and/or work in a specific setting that was not listed. As for friendships, only two participants from each group indicated a desire for fewer friends. All others indicated that they would like the same number or more friends.

Objective Quality of Life

Adaptive behavior. Adaptive behavior was measured using the Inventory for Client and Agency Planning (ICAP). There were only 28 (50.0%) ICAP scores available for the participants from Vocational Services and 58 (82.9%) ICAP score for people in Transitions. There were 40 total scores missing. The agency residential staff completes the ICAP. Therefore, if the agency did not provide residential services for the participant there would be not ICAP in the case file. There were two reasons given by the agency for case files not having completed ICAPs. First, there were group homes that do not complete the ICAP because they are contracted to provide residential services to the participants rather homes run by the agency. These homes have their own case managers. There were seven Vocational Services participants and ten Transitions participants living in one of these group homes that did not have ICAP scores. Second, there were nine Vocational Services participants who lived independently and were not in need of agency residential services. Of the completed ICAPs the mean score for Vocational Services was 40.2 and Transitions 45.1. The t-test found that the differences were statistically different ($t=-.244$, $p<.01$). Table 14 presents the comparison of ICAP mean scores by agency program.

Social Indicators. Demographics variables were reported by agency programs in Table 3. The social indicators that were reported in that table were residential setting, level of paid support in home, paid support in work/day activity, health status, income, use of physical aids, and use of behavioral treatment plan. Significant differences between Vocational Services and Transitions were found in residential setting, level of paid support in home, level of paid support in work/day activity, and expressive communication.

Relationship Between Community Inclusion and Subjective Quality of Life

Prior to performing the statistical analysis to determine the relationship between community inclusion and subjective quality of life, z scores were computed for the scores of the measure of life satisfaction, the four measures of the components of community inclusion, and the total score of community inclusion. A Pearson correlation between the total score for community inclusion and life satisfaction provided a slightly positive coefficient ($r=.245$) that was found to be significant at the .05 level. Cases were excluded pairwise. Table 15 presents the relationship between life satisfaction and the total score for community inclusion and the four components proposed to make up community inclusion. There was as a positive correlation between Life Satisfaction and the two components community integration (.385, $p<.001$) and social support (.203, $p<.05$). There was a slight correlation between life satisfaction and choice (.164, $p<.05$) although the correlation did not reach the .05 level of significance. The correlation coefficient indicating relationship between life satisfaction and social role did not reach the .05 level of significance.

To assess the collective impact of the components of community inclusion on life satisfaction, the z scores for the four variables, community integration, social role, social support, and choice were entered into a step-wise multiple regression procedure. The results are listed in Table 16. Community Integration was the only variable included in the final model. At the completion of the procedure the F value for the procedure was 18.39, $p<.001$, and the associated $r=.385$ and $r^2 = .148$.

Relationship Between Community Inclusion and Objective Quality of Life

Prior to performing the statistical analysis to determine the relationship between community inclusion and objective quality of life, z scores were computed for the scores of the measure of adaptive behavior (ICAP), the four measures of the components of community inclusion, and the total score of community inclusion. A Pearson correlation analysis between adaptive behavior as measured by the ICAP and community inclusion provided a slightly positive coefficient ($r=.285$) that was found to be significant at the .05 level. Table 15 presents the relationship between ICAP scores and the four components of community inclusion. ICAP scores were positively correlated with choice (.469, $p<.01$) and social role (.248, $p<.05$). Other components were not found to have coefficients that are statistically significant.

To ascertain the relationship between community inclusion and social indicators, a stepwise multiple regression analysis was performed. The social indicators initially identified were residential setting, work/day activity, level of paid support in work/day activity, level of paid support in home, health status, receptive communication, expressive communication, income, use of physical aids and use of behavioral treatment plan.

After considering the distributions of the variables and the correlation coefficients among them, it was determined that some predictors would not be put on the equation. Level of paid support in both home was highly correlated with the dummy variable residence (.835, $p < .01$). Level of paid support in work/day activity was highly correlated with work/day activity program (.705, $p < .01$). Given the likelihood that there would be collinearity between these variables in a regression equation, both levels of paid support were eliminated. Health status, receptive communication, and income were also eliminated from being predictors in the equation because they had very little variation among the whole sample. Health status was reported to be "good" by 86.5% of the sample. There were only three participants that did not understand verbal communication. Income had only two participants that had an income level other than "low". This left residential setting, work/day activity, expressive communication, use of physical aids, and use of behavior treatment plan. Dummy variables were created for residential setting and expressive communication.

The stepwise multiple regression indicated that the best single predictor of community inclusion was vocational/day program. The best combined predictors of community inclusion were vocational/day program and use of physical aids. After completion of this analysis for final equation including both predictors had an F value of 10.099, $p<.001$. The associated multiple r and r^2 were .398 and .159. Table 17 presents the coefficients of the regression equations.

Table 12

Comparison of Level of Satisfaction for Items on the Consumer Satisfaction Survey by Agency Program

Item	Grouping Voc Services (n=55) Frequency (%)	 Transitions (n=62) Frequency (%)
Life in General (Q1)		
Happy	42 (76.3%)	51 (78.4%)
Okay	8 (14.6%)	8 (12.3%)
Unhappy	5 (9.1%)	3 (4.6%)
Where you Live (Q2)		
Happy	32 (58.2%)	44 (71.0%)
Okay	13 (23.6%)	14 (22.6%)
Unhappy	10 (18.2%)	4 (6.4%)
Spend your Day (Q4)		
Happy	42 (76.3%)	44 (71.0%)
Okay	9 (16.2%)	15 (24.2%)
Unhappy	3 (5.5%)	3 (4.8%)
Free Time (Q6)		
Happy	37 (67.4%)	43 (69.4%)
Okay	12 (21.8%)	14 (22.6%)
Unhappy	5 (9.1%)	5 (8.0%)
Current Friendships (Q8)		
Happy	39 (70.9%)	43 (69.4%)
Okay	13 (23.6%)	10 (16.1%)
Unhappy	3 (5.5%)	9 (14.5%)
Happy Overall (Q10)		
Yes	51 (92.7%)	56 (90.3%)
No	4 (7.3%)	6 (9.7%)

Table 13

Frequency of Responses for Preference Items on the Consumer Satisfaction Survey by Agency Program

Item	Grouping Voc Services Frequency (%)	Transitions Frequency (%)
Where would you like to live?	n= 55	n=58
Where I am now	21 (38.2%)	36 (62.1%)
By myself	8 (14.6%)	6 (10.4%)
Alone with help	7 (12.7%)	3 (5.1%)
With friends	3 (5.5%)	2 (3.6%)
With family	4 (7.2%)	3 (5.1%)
In a group or foster home	1 (1.8%)	3 (5.1%)
Other	11 (20.0%)	5 (8.6%)
Where would you like to (work) spend your day?	n= 55	n=55
What I am doing now	28 (50.9%)	27 (49.1%)
I don't want to work	1 (1.8%)	3 (5.5%)
Work with job coach	9 (16.4%)	14 (25.5%)
Work with no coach	1 (1.8%)	2 (3.6%)
Volunteer	2 (3.6%)	2 (3.6%)
Work at home	3 (5.5%)	1 (1.8%)
Other	11 (20.0%)	6 (10.9%)
How many friends do you want?	n= 55	n=54
More Friends	26 (47.3%)	28 (51.9%)
Same Friends	27 (49.1%)	24 (44.4%)
Less Friends	2 (3.6%)	2 (3.7%)

Table 14

Comparison of Participants on Mean ICAP Score by Agency Programs (n=86)

	Grouping						Test of Significance
	Voc Services			Transitions			
	MEAN	SD	N	MEAN	SD	N	
ICAP Score	70.32	10.76	28	54.20	12.6	58	T=5.814*

*p<.001

Table 15

Relationship of Life Satisfaction and Adaptive Behavior with Community Inclusion

	Consumer Satisfaction Survey	ICAP
Community Inclusion Total	.245*	.285*
Community Activity and Participation Checklist	.336**	.142
Social Support Self-Report	.203*	.157
Social Role Checklist	.037	.248*
Choice Questionnaire	.072	.469**

* Correlation is significant at the 0.05 level (1-tailed).
** Correlation is significant at the 0.01 level (1-tailed).

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Table 16

Summary Step-wise Regression Analysis for Variables Predicting Subjective Quality of Life (n=108)

Variable	B	SE	ß
Step 1			
Community Integration	.205	.048	.385***

$R^2 = .148$

***$p<.001$

Table 17

Summary Step-wise Regression Analysis for Social Indicators and Community Inclusion (n=108)

Variable	B	SE	ß
Step 1			
Work/Day Activity	21.200	5.773	.385***
Step 2			
Work/Day Activity	20.946	5.643	.329***
Use of Physical Aids	13.996	5.677	.219*

Model 1 $R^2 = .111$
Model 1 $R^2 = .159$
***$p<.001$
*$p<.05$

Chapter V

DISCUSSION

In this chapter, findings from the four research questions investigated are summarized and interpreted. Implications and limitations of the findings are discussed along with observations regarding future directions for research in this area of inquiry.

The purpose of this study was to define and measure community inclusion using four components: (a) community integration, (b) social role, (c) support, and (d) choice. First, the measures were examined for adequate reliability by determining the internal consistency of the measures. Second, the relationships between the four measures were determined using Pearson correlation coefficients. Third, the relationship between community inclusion and quality of life, both subjective (life satisfaction) and objective (adaptive behavior and social indicators), were examined. Finally, scores on measures of community inclusion were examined for difference between people in different agency programs (Vocational Services and Transitions).

Findings

The methodology used to address these questions was the administration of measures of community inclusion, life satisfaction, and demographic information to consumers with mental retardation at a community mental health agency in Michigan. There were eighteen people who did not complete the entire interview process. One person elected to stop the interview, the main reason for not completing the interview was the inability to either understand or answer the question(s). It is interesting to note the characteristics related to the participants that did not complete the entire interview. The one person that elected to stop the interview was a Vocational Services' participant, while all of the other volunteers that did not complete the interview were from the Transition group.

Research Question One

The first research question asked whether the measures of components of community inclusion are reliable. The hypothesis for this question was that the measures for each of the four components of community inclusion (community integration, social support, social role and choice) would be internally consistent.

To identify the reliability of the four measures, Cronbach alphas were examined to determine internal consistency. These alphas indicated that the Community Activity and Participation Checklist (.82), the Social Support Self-Report (.87), and the Choice Questionnaire (.94) yielded adequate reliability. The Social Role Checklist yielded an alpha (.57) that is typically considered insufficient.

The alphas for the measures of community integration (Community Activity and Participation Checklist), social support (Social Support Self-Report), and choice (Choice Questionnaire) suggest that the measures are internally consistent therein supporting the hypothesis. The alpha of the measure of social role (Social Role Checklist) indicated that this measure is not sufficient and may not be considered internally consistent and subsequently does not support the hypothesis. There are possible reasons that the alpha for the measure for social role was this low. The mean score for the measure among the entire sample was three, which appears low considering the possible range. Also, a visual examination of the scores using a histogram indicated that a one third (32.5%) of participants indicated holding only two social roles. This may indicate that there were not enough items listed on the measure. It may also indicate that there are roles that were not listed that should have been such as worker, roommate, or neighbor. Despite this insufficient alpha, according to Heppner, et al. (1992), the yielded alpha does not completely limit the utility of the measure.

Research Question Two

The second research question asked if there was a relationship between proposed components of community inclusion: community integration, social role, social support, and choice. The hypothesis for this question was that there would be a statistically significant positive relationship between proposed components of community inclusion: community integration, social role, social support, and choice.

Prior to performing statistical analyses that assess a relationship, z scores were computed for the four components of community inclusion. A Pearson correlation analysis was performed using the z scores of these four components. This analysis indicated statistically significant correlation coefficients between community integration and the other three components: social support (.367, $p<.01$), social role (.364, $p<.01$), and choice (.251, $p<.01$). Statistically significant correlation coefficients were also found between: social role and choice (.205, $p<.05$) and social role and social support (.196, $p<.05$). There was no statistically significant correlation found between choice and social support (.115).

The statistically significant correlation coefficients between five of the six possible combinations of components support the hypothesis that there is a relationship. The statistically significant relationships between these constructs support the multi-component conceptualization of community inclusion. The coefficients of the relationships indicate adequate strength while also supporting the independence of each component. The acceptance of this hypothesis is done with caution given the lack of a statistically significant relationship between choice and social support.

Research Question Three

The third research question asked whether there is a relationship between community inclusion and quality of life. The hypothesis for this question was that there would be a statistically significant positive relationship between community inclusion and quality of life. Measures of quality of life for this study were subjective and objective. Subjective quality of life was defined as life satisfaction and measured as such. Objective quality of life was defined as adaptive behavior and social indicators and was measured using data found in participant case file or provided by agency staff.

Subjective Quality of Life. Prior to discussing the relationship between community inclusion and life satisfaction it is important to first discuss the measure of life satisfaction developed for this study. The mean score on the Consumer Satisfaction Survey measuring subjective quality of life (life satisfaction) was 13.08 with a range from 5 to 15. The internal consistency for the measure as reported by Cronbach's alpha is .76, which is adequate according to Heppner, et al. (1992). An analysis of the responses to each item regarding life satisfaction indicates that there were no significant differences between the participants of the two agency programs. There was also no notable difference on preferences between the participants of the two agency programs. Less than 10% of the respondents indicated that they are unhappy about their life in general, how they spend their day, how they spend their free time, and their current friendships. Participants from Transitions indicated that they are 71% are happy and 24.2% are okay with where they spend their day. Despite an indication of relevant satisfaction, when asked for preferences, approximately 50% of the respondents indicated a desire for change in the way they spend their day and the number friends that they have. The foundational purposes of community services' programs assume that living, working, and recreating in the community lead to greater life satisfaction. The above findings do not necessarily concur with these assumptions given that there was no significant difference between the groups.

The only notable difference in life satisfaction items was regarding where the individual lives. Of the Vocational Services participants, 58.2% reported being happy with their living situation in comparison to the 71% of Transitions participants that reported being happy. There was an indication of unhappiness (18.2%) that came from Vocational Services participants on where they live in comparison to only 6.4% of Transitions participant reporting unhappiness. Supporting this, only 38.2% of the Vocational Services participants stated their living preference is where they are living now. Nine (16.3%) participants indicated a desire to own their own home. Another 15 (27.3%) people indicated a desire to live on their own, either with or without support.

These findings seem to differ from previous research. Harner and Heal (1993), in research assessing psychometric properties of the Multifaceted Lifestyle Satisfaction Scale, concluded that individuals living in less restrictive environments were significantly more satisfied than individuals in more restrictive environments. Another study assessing quality of life and social integration among people from one of three residential settings, family home, group home or supported apartment (Burchard, Rosen, Gordon, Hasazi, Yoe, & Dietzel, 1992). Buchard, et al. (1992) found that persons living in group-homes reported being more dissatisfied with their residence and less happy than residents in the other two settings. No research related to satisfaction and vocational/day program services was found. Therefore, to explore this further an analysis of variance was conducted using the participant's residences. This analysis indicated that there was no significant difference. These mean satisfaction scores by residences were: family home 13.81, independent home 12.67, and group home 12.84. This again does not concur with the above cited research.

In considering the third research question, a correlation was found to be statistically significant between the sum score of community inclusion and subjective quality of life (life satisfaction) (.245, $p < .05$). There were also analyses that considered the relationships among the four proposed components of community inclusion to life satisfaction. There were statistically significant relationships found between subjective quality of life and both community integration (.336, $p < .01$), and social support (.203, p,.05). The weak relationships between life satisfaction and both choice and social role were not found to be statistically significant.

A step-wise regression procedure using all four components indicated that community integration as the only predictor variable for life satisfaction. As Storey (1993) stated, [community] integration is the necessary first step, the introduction to other forms of integration (social integration and relationships). Given that community integration has been the focus of services in the last two decades, the relationship to life satisfaction seems reasonable. The failure of the other three variables to significantly predict life satisfaction is important to consider given their importance in the operationalization of the concept of community inclusion.

Objective Quality of Life. A Pearson correlation analysis indicated that there was a significant relationship between adaptive behavior as measured on the ICAP and community inclusion, the total of the four components. The ICAP was also positively correlated with the measures of choice and social role. These findings are supported by previous research. Stancliffe's (1997) findings suggest that period of time without staff present allows for the opportunity to make more choices. Therefore given that higher scores on the ICAP indicate a lower need for staff supervision it may also indicate that opportunity for choice-making would then be greater. Similarly, Wehmeyer and Metzler (1995) found that people with mental retardation are often perceived as not capable of assuming adult roles and therefore considered not capable of making choices impacting their lives. They also found that the perception of consumer's capabilities impact the opportunities they are given to make choices.

Participants from Vocational Services have higher ICAP scores, less paid support, more social roles, and more opportunity for choice. Participants from Transitions indicated lower ICAP scores, greater paid support, fewer social roles, and lower opportunity for choice-making.

A step-wise multiple regression procedure was used to identify the relationship between community inclusion and social indicators. The criterion variable was community inclusion and predictors entered into the analysis were residential setting, vocational/day activity, expressive communication, use of physical aids, and use of behavior treatment plan. The best combination of predictors included vocational/day program and us of physical aids. While these predictors were not necessarily anticipated they are also not surprising. What was somewhat surprising was the lack of inclusion of the other three variables that were anticipated as predictors.

The above findings regarding the relationship between community inclusion and quality of life are not clearly in support of accepting the hypothesis.

Research Question Four

The final research question asked whether there are differences in scores on measures of community inclusion between the two agency programs, Vocational Services and Transitions. The hypothesis for this question was that participants from Vocational Services would have statistically significant higher scores on measures of community inclusion than participants from Transitions. In order to assert that any differences on measures are meaningful, it was first necessary to determine that these were actually two significantly different groups.

Demographic Differences

The consumers participating in this study were receiving services through at least one of two vocational/day programs, Vocational Services or Transitions. There were 15 participants who were found to be consumers of both services. After lengthy consideration, a decision was made to include the 15 with the Vocational Services consumers rather than as a separate group or as members of the Transitions group. This decision was based on the actual services each program provides. Given that people in vocational services have various activities throughout their day that may not be work related or supervised by vocational services staff it was determined that going to a Transitions' site could be considered one of these other activities.

The demographic differences between Vocational Services and Transitions participants, found to be statistically significant, were residential setting, paid support in home, paid support in vocational services/day program, expressive communication, behavior plan use, mean age, and mean ICAP score. When comparing the participants from each program given various demographic variables, differences that were found to be significant were typically ones that were anticipated. For example, participants from Transitions received a much higher number of hours of paid support in day activities in fact no Transitions participant was reported to not receive paid support and the majority of participants were reported receiving full-time support.

Another anticipated finding pertains to residential setting and subsequently the amount of paid support the participant receives in the home. A statistically significant number of participants from vocational services reported living more independently and receiving a significantly lower number of support hours. On the other hand, participants from Transitions were either living in a group home or family home, with only one participant living independently. The majority of participants from Transitions living at group homes received around the clock support although there were some Transitions participants who did not need full-time paid support, especially when sleeping.

Participants who communicated using a symbol board or gestures, noises or pictures were all from Transitions. Participants from Vocational Services could typically express themselves well using complete sentences. Transitions had four times as many participants who were utilizing behavior plans. There was also a significant difference found in relation to age. The mean age of participants in Transitions was 4.9 years higher than the mean age of participants in Vocational Services.

There was also a significant difference in mean ICAP scores between the two programs. This difference is also reasonable in that it would be expected that people with higher levels of adaptive behavior would be living and working in more independent situations. Therefore, the significantly higher scores of participants from Vocational Services are understandable. Even though these results may be expected it must also be noted that these scores were for only 68.3% of the total participants and only 50% of the participants from Vocational Services. While this does present a limitation in commenting on the sample, at least one of the reasons for the missing scores is in line with the results. The reason given for nine missing scores is that the individual is living independently and there was no need for residential services, residential services being the department that completes the consumer's ICAP. Therefore, it seems reasonable to assume that missing scores are from people in vocational services, living independently. Since the ICAP is designed to measure service needs (Bruinicks, et al., 1986) and these individuals have no service needs, it is assumed that these ICAP would be high, and possibly higher than the ones obtained.

The statistical differences between the two groups on demographic variables are important to consider in relationship to the findings of the research questions discussed below. These differences indicate the distinctness of the Vocational Services and Transitions participants. The differences support the anticipation of differences of scores on measures of community inclusion and subjective quality of life. In part, these differences, if found on the various measures, would provide some initial evidence regarding the validity of the measures developed for this study.

Community Integration

Scores on the Community Activity and Participation Checklist, the measure of community integration, indicated that there was significant difference between the Vocational Services and Transitions groups with the Vocational Services group indicating a higher number of community activities ($t=2.96$, $p<.01$).

There were several activities with noted differences between the groups. These activities included eating at a sit-down restaurant, visiting a museum, attending a concert or play, participating on a team, or participating in a league. With these activities, there were more participants from Vocational Services than from Transitions. Another notable difference in the reported activities on this measure was that people from Vocational Services reported participating in activities that were not listed. These consumers reported one or two other activities that they engage in on a regular basis. These activities included work, bingo, fishing, collector's meetings, camping, library, vacation, walking, Special Olympics, hunting, visit a friend, joy rides in the car, golfing, arts and crafts club, rollerblading, dances, bike riding, and dance class.

Given that participants from Vocational Services tend to have higher levels of adaptive behavior, greater independence, less need for paid support, and adequate expressive communication, the statistically significantly higher score from Vocational Services were expected.

Social Role

Scores on the Social Role Checklist indicated that participants from Vocational Services held a higher number of social roles ($t=1.69$, $p<.10$). Another difference between the groups was noted when participants were asked follow-up questions related to each role. For example when asked what they did as a friend, there were some differences in responses between the groups. The Vocational Services participants were able to identify more sophisticated actions that they do as friends such as talk on the telephone, meet for coffee or dinner, or help each other with problems. The Transitions participants tended to state that, as a friend they would sit next to the individual at break or talk to a friend at lunch. Another similar example of these differences came in the responses to a follow-up question asking what the person does as a church member. Twenty-two of the participants from Vocational Services who reported being members of a church reported at least one activity related to this role such as setting up before or cleaning up after services or socials, serving as a greeter before services, taking up the collection, or serving on a committee. Not one of the participants from Transitions who responded positively to being a church member reported such activity. All such responses were either pray or singing. While there could be a philosophical argument to the value to the individual of the various tasks reported as church members, the distinction between the two is clear.

Holding various social roles is common in our society. Wehmeyer and Metzler (1995), in a national survey on self-determination, found that in general "people with mental retardation are not assuming roles or engaging in activities that serve to define the individual as an adult." (p. 118) Similar to their findings, few consumers were assuming the role of spouse or parent. Wehmeyer and Metzler (1995) also note that very few consumers are homeowners. Although it was not specifically asked in the interview for this research, the researcher noted that there were no homeowners although several consumers from vocational services stated that they would like to be during the interview.

Social Support

Scores on the Social Supports Self-Report indicated that there was a significant difference between the two agency groups on the total support score ($t=1.92$, $p<.10$). Participants from Vocational Services had a higher overall mean score. When considering the mean score for each item on the measure it appears that there is not much difference in support from immediate family and friends. There does appear to be a difference between the scores for extended family, aunts, uncles, and grandparents, with participants from Vocational Services having higher scores. Support from staff was the only item with a notable difference that participants from Transitions reported to be higher than for participants from Vocational Services. This was anticipated given demographic data indicated that more than 50% of participants from Vocational Services received no paid support and those that did receive support typically received a limited number of paid support hours. Alternatively, approximately 50% of the participants from Transitions received full time paid support. Scores indicate the participants experience strong reliance on and support from staff.

An interesting difference to note is that the participants from Transitions reported a slightly higher level of support from work friends. In their review of social support research, Newton, Horner, Ard, LeBaron, and Sappington (1994) stated that most people with mental retardation rely on family, staff, or other consumers for support. Given this finding, the consumer living independently without roommates or paid staff, may experience loneliness and isolation, despite living and working in the community.

Choice

The scores on the Choice Questionnaire had a range of 10 to 36. The mean was 20.69 with a standard deviation of 7.71. The mean scores on the measures indicated significant differences between the two groups ($t=7.42$, $p<.001$). Also when examining each question, the participants from Vocational Services had higher scores than participants from Transitions. Transitions' participants reported very few opportunities for choice-making and many instances indicated that a many were given no choices at all. Therefore, it is concluded that people in Vocational Services are given more opportunity to make choices in their day to day life. Specifically, this research identifies the lack of opportunity for choice-making among individuals in a workshop setting although the lack of choice-making appears to be related to residential situation. Given that many of the questions on the Choice Questionnaire are related to home activities, an analysis was performed to determine if there are differences in choice making between the three residential settings, family home, independent home or group home. To explain this further, a one-way analysis of variance was conducted. The analysis indicated that there is a significant difference, $F=57.63$, $p<.001$, with the mean choice scores for participants being: independent home 29.48, family home 24.42, and group home 16.03. Therefore, people living in group homes are also given less opportunity to make choices in their daily life activities.

Stancliffe (1997), using the Choice Questionnaire from which questions on this study where drawn, also found that size of residence is related to choice. His findings suggest that period of time without staff present allows for the opportunity to make more choices. Therefore the less time a person has paid support the greater the opportunity for choice. This concurs with findings in this study.

Wehmeyer and Metzler (1995) found that people with mental retardation have fewer choices and less control people without disabilities. School home and work environments that are structured and overprotective do not support opportunities for consumers to make meaningful choices. They also found that the perception of consumer's capabilities impact the opportunities they are given to make choices. In summary, Wehmeyer and Metzler (1995) found that people with mental retardation are often perceived as not capable of assuming adult roles and therefore considered not capable of making choices impacting their lives.

While there was no research found to indicate differences as a result of the consumer living in a family home. This is assumed to be determined as well by the structure of the environment, the level of protection provided by the family, and the perception the family has with regard to the capabilities of the person with mental retardation.

Summary of Findings

The results of this study indicate some strengths and weaknesses in the operationalization and measurement of community inclusion. In response to hypothesis one, the alpha level for the measures of community integration (Community Activity and Participation Checklist), social support (Social Support Self-Report) and choice (Choice Questionnaire) all indicated adequate internal consistency. The corresponding alpha for the measure of social role (Social Role Checklist) could be considered insufficient, but given that this is the first use of the measure created for this study, its utility should not be totally disregarded, although further work on instrumentation appears necessary. Therefore this hypothesis will be accepted with caution.

Examining hypothesis two, there were several statistically significant relationships found between the four measures of community inclusion. Every relationship between two components was found to be statistically significant except for the relationship between choice and social support. There is no explanation for the lack of significant relationship between these two components. While this does not support the hypothesis, it does not necessarily prevent acceptance of this hypothesis. Choice has a statistically significant relationship with both community integration and social role. Social support has a statistically significant relationship with social role and an even stronger relationship with community inclusion. Given the strength of all other relationships this hypothesis is accepted while noting the lack of relationship between choice and social support. This supports the conceptualization of the construct community inclusion in that the statistically significant coefficients indicate relationships between the components. The relative strength of the correlation coefficients attained between the four measures also indicates that the four separate measures are not measuring the same construct.

The relationship between community inclusion and the measures of quality of life were anticipated in hypothesis three. There was a statistically significant relationship between the total score of community inclusion and subjective quality of life (life satisfaction) as measured on the Consumer Satisfaction Survey. There were also analyses that considered the relationships among the four proposed components of community inclusion to life satisfaction. There were statistically significant relationships found between subjective quality of life community integration and social support. The weak relationships between life satisfaction and both choice and social role were not found to be statistically significant. A step-wise regression procedure using all four components indicated that community integration as the only predictor variable for life satisfaction.

The significant differences found between agency groups on measures of community inclusion were anticipated given the differences in the two groups with regard to demographic variables. Given this, it was surprising that there were no differences found on the measure of subjective quality of life between the groups. There is no explanation for this finding. It is also unknown how this could have impacted the relationship found between community inclusion and subjective quality of life as well as the finding of community integration as the only predictor of subjective quality of life.

A Pearson correlation analysis indicated that there was a significant relationship between adaptive behavior as measured on the ICAP and community inclusion, the total of the four components. The ICAP was also positively correlated with the measures of choice and social role. A step-wise multiple regression procedure was used to identify the relationship between community inclusion and social indicators. The best combination of predictors included vocational/day program and us of physical aids. The identification of vocational/day program and use of physical aids as predictors of community inclusion seem reasonable in considering the impact that they could have on each of the various components of community inclusion. While the inclusion of these two social indicators in the model are not surprising, there is no explanation for their inclusion and the exclusion of other social indicators.

The results of analyses examining the relationship between both subjective and objective quality of life do not clearly support the acceptance of this hypothesis. First, there was a statistically significant relationship between subjective quality of life and the total score of community inclusion. There were also statistically significant relationships between subjective quality of life and both community integration and social support. There were no significant relationships found between life satisfaction and both choice and social role. A step-wise regression procedure using all four components indicated that community integration as the only predictor variable for life satisfaction.

An assumed result of community inclusion for people with mental retardation is that greater community inclusion should yield greater subjective quality of life. There were significant differences found between the two agency groups on both demographic measures and measures of community inclusion. Given this there were three unusual findings regarding subjective quality of life and the relationship to community inclusion. Foremost, there was no significant difference in the measure of subjective quality of life between the two agency groups. Second, there was no correlation between the measures of as social role and choice. And finally, there was only one component found to be a predictor of subjective quality of life using a step-wise multiple regression, community integration. These findings indicate a need for further study for the constructs community inclusion and subjective quality of life.

Second, while there is a clear relationship between ICAP scores and total community inclusion scores as well individual component measures of choice and social role, there is no relationship found with community integration and social support. Finally, the step-wise multiple regression procedure used to identify the relationship between community inclusion and social indicators identified the best combination of predictors as vocational/day program and use of physical aids. The lack of explanation for these specific predictors contributes to the inability to accept this hypothesis.

Hypothesis four anticipated differences in levels of community inclusion between participants from Vocational Services and Transitions. The demographic variables from the two groups were first tested to assure that they are actually two different groups. Participants from Vocational Services had higher ICAP scores, less paid support, more social roles, and more opportunity for choice. Participants from Transitions indicated lower ICAP scores, greater paid support, fewer social roles, and lower opportunity for choice-making.

Given that participants from Vocational Services tend to have higher levels of adaptive behavior, greater independence, less need for paid support, and adequate expressive communication, the higher scores from Vocational Services on total community inclusion as well as each of the four individual components, were expected. There were significant differences in on the community inclusion total, and the specific measures of community integration and choice. There were also differences found on social role an social support that were not found to be significant at the $p<.05$, although they were significant at the $p<.10$. While there were only differences found at the $p<.05$ level for community integration and choice, the differences found for social role an social support are worthy of consideration. Therefore this hypothesis is also accepted but again with caution given the level of significance for social role and social support.

In conclusion, the goal of this research was to define and measure community inclusion. This study identified four possible components of the construct and identified measures of each. The measures of community integration, social support and choice were all determined to be internally consistent. There were significant relationships found between the five of the six possible combination of measures appropriate identifying relationship as well as independence of the measures. Although there were some issues involved in the findings, the total score of community inclusion was related to quality of life. Various components were related to both subjective and objective measures of quality of life. There were significant differences found between two different agency groups on total community inclusion. Differences were found between the groups for community integration and choice at the $p<.05$ and between the groups for social support and social role at the $p<.10$ level. The findings seem to indicate, that while there is still a need for further research, this study has made a significant contribution to that goal.

Limitations

There are limitations that must be considered in the interpretation of the findings of this study. These limitations come from both decisions made in planning the study and issues that occurred when conducting the study. This study was limited in that the data was collected from one tri-county community mental health agency in the state of Michigan, therefore limiting the ability to generalize results. Also, the agency serves approximately 800 people with mental retardation. There were 294 contacts made to consumers or guardians requesting participation. All 126 consumers that agreed to participate were interviewed. This limits the ability to generalize results to this agency. There have been limitations with this study that could be addressed. Specifically, future research could be conducted in other community agencies both in the state of Michigan and in other states.

Despite the 126 interview times scheduled there were only 108 interviews fully completed. During the interview process there were occasions when the participant could not comprehend a question enough to come up with a response. This happened more frequently when a participant was asked an open-ended question.

Collecting data in various settings may be considered a limitation. Several participants were interviewed in their homes or at their work sites. Often there was a parent, spouse, roommate, co-worker, or staff member present or close-by during the interview all at the participant's consent. Despite the consent to have another person present, this could have influenced the responses given.

Given her internship experience with the agency, the researcher was familiar with the agency and many consumers. This could be considered both an advantage and limitation. Researchers advocate a more egalitarian relationship between the researcher and the participant (Kelly, Dassoff, Levin, Schreckengost, Stelzner, & Altmann, 1988). This researcher's prior knowledge of the agency and consumers as well as their prior knowledge of her, assisted in the establishment of an egalitarian relationship with participants in this interview process. Kelly, et al. (1988) refers to this as a period of reconnaissance in which the researcher develops both working relationships and an understanding of the culture.

Another limitation is the reliance on self-report from people with mental retardation. These issues include acquiescence (Heal & Chadsey-Rusch, 1985; and

Matikka & Vesala, 1997), test-retest reliability, responsiveness, consistency, and informant reliability (Heal & Sigelman, 1996).

Acquiescence is the tendency to respond affirmatively regardless of question. While previous research has noted several issues in the assessment of people with mental retardation, it was more important to this research that the information come from the consumer rather than another informant interpreting the life of that individual.

Although the initial intention was not to increase motivation to participate, receiving five dollars for the interview became an obvious motivation for most participants. Given, there is no way of knowing the impact of this incentive on responses, it was important to this researcher that I acknowledge the sacrifice of their time and also my gratitude.

Implications of Findings

There are several implications from this exploratory study. The hypotheses in this study anticipated internal consistency of measures, relationship between measures of community inclusion, relationship between community inclusion and quality of life, and differences in scores on measures of community inclusion between the agency programs. While the hypotheses regarding the internal consistency and relationship of measures were accepted, as well as the programmatic differences in scores of community inclusion were accepted with caution, acceptance cannot be made regarding the meaning of community inclusion and its relationship to participants' life satisfaction. With this in mind, implications with regard to future research, practice, and training are discussed.

Implications for Future Research

Of course there are many implications for future research. First, the conceptualization and operationalization of community inclusion need to be investigated further. Anticipated internal consistency, relationships between the measures, and differences between the two agency groups on the measures support the conceptualization. The relationship of the components to quality of life clearly indicates a need for further investigation of the construct. Further investigation needs to address both the operationalization of this construct as well as the measurement issues.

In addition, future research should address best practices and intervention strategies. This could be addressed in using various research designs. Experimental designs could identify changes in the experience of community inclusion given modification in life situations specifically in home, work or leisure. Experimental methodology would also be the means to evaluate intervention strategies. The use of a qualitative research methodology could enlighten our understanding of the experience of community inclusion. An intensive study of individual situations and experiences could provide knowledge on process that leads to outcome.

The statistically significant relationships found between community integration and the other three components of community inclusion (social role, social support, and choice) find support from Storey's (1993) "first step" belief. As Storey (1993) stated, [community] integration is the necessary first step, the introduction to other forms of integration (social integration and relationships). Given that community integration has been the focus of services in the last two decades, the impact of community integration on the psychological and social experience of community inclusion should be further examined in regards to people who are living and working in integrated and those that continue to live in segregated settings..

Practice

When given in an interview format, most of the participants in this study had very little trouble responding to the questions. The interview format eliminates the consumer's need to be able to read and complete the measures. The measures used in this study could be used as interview protocols to identify strengths and needs of individuals seeking services. While these measures may be appropriate for an interview process, further research needs to identify their value as reliable measures of community inclusion and quality of life.

There have been many interventions designed to advance community inclusion and the components that have been used to operationalize community inclusion in this study. There are numerous interventions that could be employed, so numerous that it is not in the realm of this study. Ultimately, professionals attempting to implement programs promoting community inclusion are urged to consider the saliency of consumer differences along with their needs and desires.

Training Personnel

While interventions typically address the need of the consumer, there appears to be a need for interventions to inform and train staff. For example, as identified in both this and previous research, there is a lack of opportunity for choice-making among individuals in both workshop and structured residential settings. This lack of choice-making appears to be related to staff perception of the consumer or possibly people with mental retardation in general. Staff training should address ways to promote self-determination.

Conclusions

This research proposed that community inclusion could be operationalized by the sum of four components: (a) community integration, (b) social role, (c) social support, and (d) choice. The findings from this study provided some knowledge from which to build. These measures appear to be adequate tools in helping community agency staff assess individual inclusion needs so steps may be taken to increase individual community inclusion. While the field of rehabilitation as well as the field of mental retardation supports a philosophy of community inclusion, it is important that it continue to be operationalized further and subsequently measured.

Lord and Hutchinson`(1993) stated "one of the cruelest myths experienced by people with disabilities is that they do not have the same social needs as other citizens." (p. 10) While there have been numerous changes made in the lives people with mental retardation, these changes are not enough. This research has taken one step in looking at the experience community inclusion for people with mental retardation. It is important that this research be built upon to further meet the social needs of this population.

APPENDICES

APPENDIX A

Guardian Transmittal Letter

Dear Guardian:

My name is Margaret Sebastian and I am a doctoral student at Michigan State University. As a part of my training experience I am very interested in learning more about people with developmental disabilities and their experience in the community. This survey process will be monitored by both CEI/CMHB and Michigan State University.

To do this, Community Mental Health needs your permission to release the name of the person for whom you are the guardian. They cannot release this information without your permission. Participation in this study is important! This research may help mental health professionals to better serve people with developmental disabilities.

Your consent would give me permission for the following:

1) participate in a face to face interview with the consumer lasting approximately 30 minutes;
2) access to consumer's case file; and
3) information from agency staff regarding the consumer.

Participation is completely voluntary. The decision whether or not to consent to participation will not jeopardize the services you or the consumer receives. The consent of the consumer will also be requested prior to the interview. The consumer will be given the opportunity to refuse to participate in the survey, refuse to respond to any question, or stop participating in the survey at any time. **All results will be confidential**, and will remain anonymous in any report of research findings.

As an incentive to participation in the survey, consumers who complete the interview will receive $5.00.

If you agree to consent to participation in the survey, please complete the attached consent form and return it in the enclosed self-addressed stamped envelope.

Thank you in advance for your anticipated support and cooperation. If you have any questions concerning this evaluation project, please contact me at (517) 351-9291.

Sincerely,

Margaret Sebastian
Graduate Student
Michigan State University

APPENDIX A

Consent Form and Authorization for Release of Information

Client Name:
Date of Birth:

I give my permission to release information pertaining to my child's/ward's care.

From:		**To:**	**Margaret M. Sebastian**
	____________________		**Michigan State University**
	____________________		**401C Erickson Hall**
	____________________		**East Lansing, MI 48823**

I understand this record may contain mental health, drug and/or alcohol use/abuse history, HIV/AIDS information, or ARC information as applicable to my child's/ward's case.

The purpose of the release is for research purposes.

The specific records/information requested include:

1) **assessments,**
2) **physician's history and physical,**
3) **psychiatric/psychological evaluations/tests**
4) **verbal exchange information from agency staff**
5) **verbal exchange information from the consumer.**

This authorization will expire one (1) year from the date of signature.

I understand that I may withdraw this authorization in writing at anytime unless action has already been taken based on this consent. I have read or have had read to me this consent form and understand what it means.

______________________________ ________________
client/parent/guardian signature Relationship Date

____
witness to the above signature Date

THE INFORMATION RELEASED WITH THIS AUTHORIZATION IS CONFIDENTIAL. FURTHER DISCLOSURE OF THIS INFORMATION IS PROHIBITED UNLESS OTHERWISE PERMITTED BY FEDERAL AND STATE LAWS.

(Please return this form in the enclosed self-addressed stamped envelope).

APPENDIX B

Community Inclusion Research-Volunteer Protocol

Dear Consumer:

I am a student at Michigan State University. I am doing research on community inclusion. In order to learn about community inclusion I would like to hear about your life and experiences. I would like to have your permission to release your name to her. **Your participation is extremely important!** The information that you provide may help better serve the people in this program.

If you agree to participate in this study, I will contact you and arrange a meeting time to ask you questions about your life and activities in the community. The interview should take no more than 30 minutes to complete. Your consent would give me permission for the following:

1) participate in a face to face interview with the consumer lasting approximately 30 minutes;
2) access to your case file; and
3) information from agency staff about you.

Participation is completely voluntary. This means that you can not be made to participate. It also means that if you choose to participate you may quit at any time. Any information you provide will be held in strict confidence. This means that no one except me, the researcher, (Margaret Sebastian) will know the answers that you give. All results will be confidential, and you will remain anonymous in any report of research findings. This means that what you say to her is a private and you will never be identified as having said something. She may use some of the things that you say to present this research but she will not tell anyone that you were the one that said it.

If you are selected to participate and you complete the interview, you will be paid $5.00. If you would like to volunteer to participate in this study please let me know and I will give your name to the researcher. Again if you are selected Margaret will contact you to arrange meeting times.

Thank you for your support and cooperation. If you have any questions concerning this evaluation please call Margaret Sebastian at (517) 351-9291. Thank you for your support and cooperation.

Sincerely,

Margaret Sebastian
Graduate Student

APPENDIX B

Consumer Consent Form

Program Name:

Participant Name: ______________________________

Address: ________________________

Phone:____________________________________

Best time of day to interview:

By completing and returning this form, you verify that you have received voluntary agreement from above individual to participate in the research that will be conducted by Margaret M. Sebastian at Michigan State University. You have also witnessed the signing of the consent form.

Signature: ___________________________
Position: ___________________________

Sign and Return the consent form to:
Richard Coelho
913 W. Holmes Suite 280
Lansing, MI 48910

APPENDIX B

Community Inclusion Informed Consent Form

1. I have freely agreed to participate in the study being conducted by Margaret M. Sebastian from Michigan State University.

2. This study has been explained to me and all of my questions have been answered to my satisfaction.

3. I agree to complete all interviews with Margaret M. Sebastian and to allow the interviews to be audio taped.

4. I agree to allow Margaret M. Sebastian to gain information from my case files, program records, my case manager, and CSDD staff that are familiar with me.

5. I understand that the information that I provide in the interview is confidential/private and that no information concerning my case or something I said will be attributed to me. No individual will be identified.

6. I understand that failure to participate in this study or to quit at any point during the study will in no way impact my services from CSDD or any other agency.

7. I understand that participation in the interviews are for research and there is no treatment. involved

8. I understand that agreement to participate in this study will remain in effect for 60 days from the date of this agreement.

9. I understand that upon completion of the second interview I will receive five dollars from the researcher, Margaret Sebastian.

Signed: ______________________ Date:

APPENDIX C

INTRODUCTION and CONSENT

Dear Consumer:

I am a student at Michigan State University. I am doing research on community inclusion. In order to learn about community inclusion I would like to hear about your life and experiences. I would like to have your permission to release your name to her. **Your participation is extremely important!** The information that you provide may help better serve the people in this program.

Participation is completely voluntary. This means that you can not be made to participate. It also means that if you choose to participate you may quit at any time. Any information you provide will be held in strict confidence. This means that no one except me, the researcher, (Margaret Sebastian) will know the answers that you give. All results will be confidential, and you will remain anonymous in any report of research findings. This means that what you say to her is a private and you will never be identified as having said something. She may use some of the things that you say to present this research but she will not tell anyone that you were the one that said it.

By completing and returning this survey interview, you indicate your voluntary agreement to participate. As a way of thanking you for your participation, **if you choose to complete this survey you will receive $5.00.**

So, can we start the survey?

YES ____________ **NO**____________________

THANK YOU!

APPENDIX D

Community Activity and Participation Checklist Form

Within the past thirty days have you:	YES	NO
1. Been to a grocery store or food store?	1	0
2. Been to a department store such as Meijers, Target, or WalMart?	1	0
3. Seen a movie in a movie theater?	1	0
4. Watched a rented movie with friends or family?	1	0
1. Eaten at a fast food restaurant such as McDonald's or Wendy's?	1	0
2. Eaten at a sit down restaurant? (where you are waited on)	1	0
3. Stayed overnight at a hotel/motel?	1	0
4. Been to a recreation or exercise facility such MAC or the Y?	1	0
5. Been to a park?	1	0
6. Been to a mall?	1	0
7. Been to a bar or dance club?	1	0
8. Been to an ice cream or frozen yogurt shop?	1	0
13. Stayed overnight at a friends?	1	0
14. Attended a church or synagogue service or social?	1	0
15. Volunteer at a community event?	1	0
16. Gone to a bowling alley?	1	0
17. Gone to a pool hall?	1	0
18. Visited a museum?	1	0
19. Attended a concert, play or other musical production?	1	0
20. Participated in a league such as bowling, d arts, or pool?	1	0
21. Participated on a sports team such as soccer, or football?	1	0
22. Attended a sporting event such as a football or basketball game?	1	0
23. Participated in a support group?	1	0
24. Other?	1	0
25. Other?	1	0

APPENDIX E

SOCIAL ROLE CHECKLIST

Read to Participant: *I would like to know the social roles which you perform. Please answer the following questions.* **Interviewer**: *Read each question to the participant. If the participant responds "yes", read the follow-up question(s) and record the response.*

	YES	NO	Follow-up questions if response is yes:
1. Are you someone's friend?	1	0	a. What are some things that you do as this person's friend?
2. Are you a member of a church?	1	0	a. What are some things you do as a member of your church?
3. Are you a member of a club?	1	0	a. What is your role in the club? (e.g., officer, active member, committee chair, etc.)
4. Have you ever participated in an advocacy group like Partners in Policy Making or People First?	1	0	a. Which group? b. What did you do in this group? c. How long did you participate?
5. Have you ever been a member of a support group?	1	0	a. How have you supported others in the group?
6. Are you a husband/wife or boy or girlfriend?	1	0	a. What do you do as a -------?
7. Are you a parent?	1	0	a. What special things do you have to do as a parent?
8. Have you helped someone lately?	1	0	a. How did you help them?
9. Do you volunteer anywhere?	1	0	a. What do you do as a volunteer?
10. Are there any other roles that you have?	1	0	a. What are the responsibilities of this role?

APPENDIX F

Social Supports Self-Report

Consumer Identification number: ______________________________

Read to Participant: *Now, I would like to know about relationships that you have. Please answer the following questions.*
Interviewer*: Read each question to the participant and record the response.*

1. Do you live with anyone? 1. YES 2. NO
2. Are you married?

1) YES [If yes] Spouse's name _______________

2) NO [If unmarried] Do you have a boyfriend or girlfriend?
    1) YES [If yes] What is his or her name? _____________
    Where does s/he live? _____________
    2) NO

3. Is your mother alive? 1) YES [If yes] Where does she live? ___________
2) NO _______________

4. Is your father alive? 1) YES [If yes] Where does he live? _____________
2) NO _______________

5. Do you have any :

a. brothers?	1. YES 0. NO	**If yes, how many?**	If yes, where do they live?
b. sisters?	1. YES 0. NO	**If yes, how many?**	
c. aunts?	1. YES 0. NO	**If yes, how many?**	
d. uncles?	1. YES 0. NO	**If yes, how many?**	
e. grandparents?	1. YES 0. NO	**If yes, how many?**	

6. Of those people who do you get along with best? _____________________

APPENDIX F

7. Do you have any friends?

1) YES [If yes] Who are they? ______________________________

2) NO

8. A. Who is your best friend? _______________
B. Where does s/he live?_____________

9. A. Who is your second best friend? _______________
B. Where does s/he live? _____________

10. Do you have any roommates?
1) YES [If yes] Who are they? ______________________________

2) NO

11. Do you have friends at work?
1) YES [If yes] Who are they? ______________________________

2) NO

12. Do you have any staff?
1) YES [If yes] Who are they? ______________________________

2) NO

13. Is there any body else important to you?
1) YES [If yes] Who? ______________________________

2) NO

14. If you needed something or you are lonely is there someplace you can go to be with other people? _________________

1) YES [If yes] Where? ______________________________

2) NO

APPENDIX F

DIRECTIONS :

1) List each important person or group of persons (family, staff, friends, partner) using the responses identified above in the first column of the table below.
2) Ask the listed questions about each support source
3) Use three color coded cards with the three response choices on them to be placed in front of participant. Less verbal participants may chose to point to a particular card rather than speak their selection. If the person cannot read, until they are familiar with the choices, be sure to give the choices in random order to control for response biases.
4) The choices are:

3) a lot (red card)
2) sometimes (yellow card)
1) not at all (blue card)

5) The questions to use are:

A. How often do you see your ___________ or talk to ____________ on the phone?

B. How often do you talk to __________________ about your feelings?

C. How much do you like ____________________?

D. How much does __________________ help you with your problems?

E. How much do you help ___________________ with his/her problems?

Scoring:

Subscale for each support source: sum items a-e for that support source. If they do not have family or a partner or staff, then that subscale score is zero. They receive no support and give no support to that source.

Also reciprocity subscale can be computed by summing item across support sources.

APPENDIX F

3) a lot (red card) 2) sometimes (yellow card) 1) not at all (blue card)
0) not appropriate

Name	**A. Talk**	**B. Feelings**	**C. Like**	**D. Feelings**	**E. Reciprocity**
A. Spouse/Sweetheart					
B. Mother					
C. Father					
D. Brothers					
E. Sisters					
F. Aunts					
G. Uncles					
H. Grandparents					
I. Roommates					
J. Staff					
K. Work Friends					
L. Best Friend					
M. Others					

APPENDIX G

CHOICE Questionnaire

Interview instructions: Some items, like item two have more than one question to help clarify the degree of choice for that item. Ask each question and wait ten seconds for a response before asking the next question for that item. Probe responses if necessary to aid accurate scoring. Some suggested probes are listed in parentheses after the items. These suggested probes do not have to be asked if the person participates actively in the decision (e.g., is asked for his or her ideas or preferences).

- Category 1: Others decide most or all of the time and the person has little or no say. Choose this category if the person has little or no say regardless of whether it is staff, family, or other residents who make the decision or prevent the person from doing what he/she wants. If the person has had no opportunity to make the decision this would generally be scored as 1. With item 3 for example, someone who never cooks, never has the opportunity to decide what he or she will cook and so is scored as not making that decision (i.e., category 1). Likewise, if the person does not know who makes a given decision give a score of 1. If the person does not genuinely participate in the decision then he/she may simply not know who actually decides. Scoring for some items includes two or more alternative standards linked by the word OR. Give a score of 1 on that item if any one of the standards are met.

Example: Item 2 is about deciding which jobs to do around the house. Take the example of someone who shares an apartment.

- Category 3 - The roommates work out between them which jobs need to be done and which jobs each will perform. There is no direct involvement from family or staff in the process other than occasional comment or reminder.

- Category 2 – The roommates along with family or staff, work out the jobs to do and who will do them. They formalize this with a roster or list. That is the roommates participate in choice with the help of others.

APPENDIX G

CHOICE QUESTIONNAIRE

Identification Number____________________

A. Who decides what time you go to bed? (Does anyone tell you what time to go to bed?, Are there any rules about what time you should go to bed?)		
3. I decide for myself	2. I usually decide with some help. Sometimes others tell me.	1. I have a set bedtime OR others mostly tell me when to go to bed.
B. Who decides which jobs you do around the house? Do you have a set of jobs or a roster? Who works out the roster/set jobs?		
3. I/We choose the jobs I/we do.	2. I/We usually choose with the help of staff make the roster.	1. Others mostly tell me. OR My jobs are set up by a roster or a list made up by someone else.
C. Can you get yourself a drink or something to eat whenever you want? Anytime? Do you have to ask someone first?		
3. Yes, I can have a drink whenever I want.	2. I can usually have a drink or snack but I have to ask first.	1. No. I am usually allowed to have a drink or snack OR I can only have them on special occasions.
D. What rules are there for using the telephone? Can you make a call whenever you want?		
3. I can use the phone whenever it is already in use.	2. I can usually make calls but I may have to ask staff.	1. I am unable or not allowed to use the phone OR my phone use is restricted.
E. Who decides if you can have a pet (like a bird, dog, or cat) if you want one? Can you have any kind of pet that you want? Do you have to ask before you can get a pet?		
3. I can have a pet if I want with not restrictions.	2. There are restrictions on the type of pet because of the landlord OR I have to ask someone first.	1. I am not allowed to have a pet Or others decide. I do not have a say.

APPENDIX G

F. What are the rules about you being in the house by yourself (without staff)? Can you be in the house by yourself if you want to? Anytime?		
3. I can be by myself at anytime with no restrictions.	2. Sometimes I can be by myself (in certain situations)	1. I am not allowed to be in the house by myself.
G. Who decides how much money you take out of the bank? Can you take out as much money as you want? Do you ask anyone how much to take out?		
3. I decide without help and with no restrictions on how much to withdraw.	2. I have help deciding how much to take out OR I ask someone how much to take out OR I have a limit on how much I can withdraw.	1. Others decide how much I withdrew. I am not consulted.
H. Do you drink alcohol like beer or wine? Who decides if you can drink beer or wine? Do you have to ask anyone to drink alcohol?		
3. I decide.	2. I decide with help (I ask someone (staff or family) OR I don't drink because of medical reasons.	1. Others decide (they tell me if I am allowed to drink).
I. Does anyone stop you from going out? Is there anywhere you are not allowed?		
3. I can go wherever I want. No one stops me.	2. There are one or two place that I am not allowed to go.	1. Others often stop me from going out OR I almost always go with staff or family.
J. Can you come home late from work/day activities? Do you have to tell anyone first or call in? (Do you get in trouble for coming home late?)		
3. I can come home late whenever I want. I do not have to tell anyone first.	2. I can be late if I want, but I am supposed to ask/tell someone first or call first. I get into trouble if I do not call first.	1. Other decide OR I am not allowed to be late OR I have no opportunity to stop off after work and get home late.
K. What happens if you wan to take a day off work when you are not sick? If you just feel like having the day off? Do you have to ask anyone first?		
3. I decide. I might lose pay though.	2. I decide with help. I ask others (family or staff).	1. Others mostly decide, I have no real say. OR I am not allowed to I have to attend work/day activities.
L. Overall, would you say that your life is free so that you can choose what you want? All of the time?		
3. Yes, definitely.	2. Yes most of the time.	1. No. I cannot do what I want.

APPENDIX H

Consumer Satisfaction Survey

Identification Number: ______________________________

Directions:(*Read to the interviewee*) Sometimes during this interview I will ask you a question and you can give me an answer. Sometimes during this interview we are going be using a scale. (*Show scale*). This scale shows three different ways in which you may feel HAPPY, OKAY, or UNHAPPY. This is happy (point). This is okay (point). This is unhappy (point).

1. Do you feel Happy, Okay, or Unhappy about your life in general? (Circle the response that best describes the response).

1. **Happy**
2. **Okay**
3. **Unhappy**

2. Do you feel Happy, Okay, or Unhappy about where you live? (Circle the response that best describes the response).

1. **Happy**
2. **Okay**
3. **Unhappy**

3. Where would you like to live? (Circle the response that best describes the response)

1) Where I am living now.
2) By myself.
3) Alone but with some help.
4) With some friends.
5) With my parents or sibling.
6) In a group or foster home.
7) With relatives other than my parents or brother/sister.
8) OTHER (specify) ______________________

APPENDIX H

Consumer Satisfaction Survey

4. Do you feel Unhappy, Okay, or Happy about where you spend the day? (Circle the response that best describes the response).

1. **Happy**
2. **Okay**
3. **Unhappy**

---

5. Where would you like to work or spend your day? (Circle the response that best describes the response).

1. **I want to stay with what I am doing now.**
2. **I do not want to work.**
3. **I want to work at Transitions full-time.**
4. **I want to work in the community with a job coach.**
5. **I want to work in the community with no job coach.**
6. **I want to volunteer in the community.**
7. **I would work in my home.**
8. **Other (please specify):**

---

6. Do you feel Unhappy, Okay, or Happy about how you spend your free time? (Circle the response that best describes the response).

1. **Happy**
2. **Okay**
3. **Unhappy**

---

7. How would you like to spend your free time?

APPENDIX H

Consumer Satisfaction Survey

8. Do you feel Happy, Okay, or Unhappy about your current friendships? (Circle the response that best describes the response).

1. **Happy**
2. **Okay**
3. **Unhappy**

9. Which would you say is most true about your wish about the number of friends you would like to have. (Read responses and circle the response that best describes the consumer's response)

1. I would like to have the same number of friends that I have now.
2. I would like to have fewer friends than I have now.
3. I would like to have more friends than I have now.
4. OTHER (specify):

10. Are you happy with your life, overall?

1) Yes

2) No

11. What is it about your life that makes you happy?

12. What is it about your life that makes you unhappy?

13. What is it about your life that you would like to change?

APPENDIX I

Demographic Information

A) **Identification number:**

B) **Date of Birth:**

C) **Age: (in years)**

D) **Current Residential Setting: (circle)**

1. with family
2. with friends
3. independent/by self
4. nursing home (Name) ________________
5. AIS home (Name) ________________
6. AFC home (Name) ________________
7. CMHB Operated home (Name) ______________
8. Contract Operated Home (Name) _________
9. Other:

E) **How many hours of paid support does the individual receive per week? Please provide the number of hours and number of consumers per each staff.**

1. In Day Activity or Work	A.	__________	hours
	B.	__________	consumers per one staff
2. In Daily Living or at Home	A.	__________	hours
	B.	__________	consumers per one staff

F) **Day Activity (circle appropriate program)**

1. Vocational Services (specify work site______________)
2. Transitions North
3. Transitions South
4. Transitions Central
5. Other (Specify)

G. **Gender: 1) Male 2) Female**

H. **Given general knowledge of this individual's health, would he/she be**

1) Excellent
2) Good
3) Fair
4) Poor

APPENDIX I

I. **Given general knowledge of this individual should he/she be described as:**

1) **High Income**
2) **Moderate Income**
3) **Low Income**

J. **Circle the one statement below that best describes the individual's receptive communication.**

1) **Understands spoken language**
2) **Understands structured sign language**
3) **Understands by depending on lip reading or written materials**
4) **Understands using gestures, facial expressions, or simple pictograms**

K. **Circle the one statement below that best describes how the individual communicates with others?**

1) **Verbally using sentences and phrases**
2) **Verbally using a limited number of words**
3) **Using structured sign language**
4) **Using a symbol board or writing**
5) **Using gestures and/or noises, or primitive symbols**

L. **Does the individual need any of the following physical aids? (Circle all that are needed)**

1) **glasses**
2) **wheelchair**
3) **hearing aid**
4) **adaptive equipment to eat**
5) **g or j tube**
6) **cane, crutches, or walker**
7) **helmet**
8) **hand splints**
9) **Other**

M. **Is the individual on a behavior treatment plan? 1) YES 2) NO**

N. **ICAP Total Score/Service Score** ________________

O. **Community Integration** ________________

P. **Social Role Score** ________________

Q. **Social Support Score** ________________

R. **Choice Score** ________________

S. **Life Satisfaction Score** ________________

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