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THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE PURSUIT OF COMMUNITY-INCLUSIVE OPPORTUNITIES AND EXPERIENCES FOR PEOPLE WITH MENTAL RETARDATION

By

Richard James Visingardi

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

College of Social Science
School of Social Work
Political Science Department

2000

ABSTRACT

THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE PURSUIT OF COMMUNITY-INCLUSIVE OPPORTUNITIES AND EXPERIENCES FOR PEOPLE WITH MENTAL RETARDATION

By

Richard James Visingardi

Efforts of promoting citizen rights and responsibilities of people with mental retardation have been predominate over the past fifty years. Contemporary efforts are beginning to explore two key concepts: self-determination and community inclusion. Self-determination places the individual with the disability as driving her/his life desires and decision-making, controlling resources necessary for supports and accommodations, and involving other people who the individual has identified as significant in his/her life planning process. Community inclusion involves opportunities and experiences for an individual to enhance his/her quality of life through the development of reciprocal relationships with ordinary people and natural places in the community.

Organizations responsible for providing supports and services for people with mental retardation influence how self-determination is practiced and how opportunities and experiences for community inclusion are pursued. The purpose of this study was to determine the extent the organizations

contributed to and detracted from the concepts, and to examine variations in the manner organizational members aligned with the concepts and each other.

Four organizations in a mid-western state, involved in the Robert Woods Johnson Self-determination initiative, participated in this study. Fifty-three organizational members participated by completing an individual survey and being involved in focus groups. A content analysis was also completed examining key organization documents.

The findings revealed organizational members had some differing perceptions regarding the manner in which the organizations were operating relative to self-determination and community-inclusion. Also, the findings indicated that although the organizations had demonstrated sound accurate and consistent commitment to the values and understanding of the concepts of self-determination and community inclusion, actual practice did not entirely reflect the intent of the concepts.

Limitations, such as sample size, sampling methodology, and general design considerations, require that this study be categorized as exploratory and primarily rendering impressions derived from systematic inquiry. However, the learning from this study does provide for a better understanding of organizational and institutional arrangements relative to the concepts studied and a better understanding of both practice and future research considerations.

I dedicate this manuscript to the memory of my grandmother, Rose Visingardi, a woman of unconditional love, wisdom, compassion, and beauty and the most self-determined individual I have ever met, to Rebecca, an amazing young spirit who has provided me a great deal of inspiration, and most of all, with love to the central part of my being, my children, Jamie, Jennifer, Jacob, and Jody, and my wife Julayne.

ACKNOWLEDGMENTS

I appreciate the kind support, sound guidance, and demand for excellence provided by my Dissertation Committee; Dr. Rena Harold, Dr. Mark Wilson, and Dr. Harry Perlstadt and, in particular, my Chair, Dr. Paul Freddolino.

Without the professional contributions of Mr. Glenn Stanton (Content Editor), Ms. Shirley Ballard (Statistics Consultant), Ms. Jeralyn Lowe (Focus Group Co-Facilitator), Mr. Jeff Fudesco (Research Assistant) and, in particular, Ms. Tammy Quillan (Technical Editor and Coordinator), simply stated, this thing would have never got done. Thanks gang! I also very much appreciate another group of folks who ultimately made this dissertation possible--the organizations and their staff and clients that so willingly consented to participate in this research effort.

To my work mates and friends at the Michigan Department of Community Health, a special thanks for your support and tolerance of me while I worked "two jobs" to complete this dissertation.

I have lived a great life, full of adventure, and excitement. In my journeys, I have meet so very many wonderful people, people who have moved me, touched me. I am not afforded space in this manuscript to list each of them. There are, however, several people that I must mention,

people who have inspired me so deeply, touched my heart and soul, embraced my naive and passionate romantic nature, influenced the good in what I am, and who I love and cherish and who particularly motivated me to complete this endeavor. To my extended Italian family; Dave, Holly, George, Don, Patrick, Tammy, Bill, Jeff, Marilyn, Judith, Chris, Clint, Cheryl, Anne, Art, Dawn, Marty, Jeri, and, particularly to Becky and Glenn, who provided me with much tender loving care throughout the completion of this rewarding yet sometimes painful and lonely task, I carry you in my heart for all time with eternal love and gratitude.

And to my spiritual guru, Jimmy Buffett, whose wisdom and poetry continuously reminds me of what is really important and whose musical messages carried me through the completion of this dissertation, thank you. I leave the reader with some relevant words of wisdom from Mr. Buffett's "Jimmy Dreams":

"Take it all in, it's as big as it seems,
count all your blessings, remember your dreams."

Peace.

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THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE PURSUIT OF COMMUNITY-INCLUSIVE OPPORTUNITIES AND EXPERIENCES FOR PEOPLE WITH MENTAL RETARDATION

VOLUME I

By

Richard James Visingardi

CHAPTER 1: INTRODUCTION

There has been a sustained, evolving concern for promoting the rights and responsibilities of full citizenship for people with developmental disabilities over the second half of the twentieth century (Parham, Hart, Newton, and Terraciano, 1983; Moss, 1984; Menolascino, Gilson, and Levitas, 1986; Chiles, 1987; Plum, 1987; Holbrook and Percy, 1992; Perlin, 1994; Pfeiffer, 1993; Tower, 1994; Weber, 1994; Weber, 1994; Henry, Keys, and Jopp, 1996; Mackelprang and Salsgiver, 1996; Huang and Rubin, 1997; Fleischer and Zames, 1998; Nerney, 1998). Self-determination and community inclusion are contemporary philosophies and practices intended to promote an individual's right to be a full participant in natural community processes and places (Mount, Beeman and Ducharme, 1988; Perske and Perske, 1988; O'Connell, 1988; Amando, Conklin and Wells, 1990; Sullivan, 1992; Harper, 1996). To develop an understanding of self-determination and community inclusion, this literature review is organized into three components: concepts, framework, and context.

It should be noted that a majority of the literature presented in this review is derived from the field of developmental disabilities. Additional relevant resources from other fields and disability groups are also included.

Conceptual Considerations

Self-determination and community inclusion are the concepts being defined. Self-determination is developed through a set of principles that place individuals with disabilities as driving her/his life desires and decision-making, controlling resources intended on providing for support and accommodation, and involving other people whom the individual has identified as significant in her/his life (O'Connel, 1988; Hoffman and Field, 1995; Wolfe, Ofiesh, and Boone, 1996; Nerney, 1998). Person-centered planning offers a methodology for pursuing the development and related actions of self-determination practices (Heller, Factor, Sterns, and Sutton, 1996). Thus, person-centered planning is intended to be the conduit for self-determination.

Community inclusion involves outcomes associated with an individual acquiring access and opportunities in the mainstream of community life (Peterson, 1993). These opportunities are related to the development of relationships with people and places in the natural community (Mount, Beeman, and Ducharme, 1988; O'Connell, 1988; Amando, Conklin, and Wells, 1990; O'Brian and Lovett, 1992; Mount and Zwernik, 1994; McNulty, Connolly, and Wilson, 1996). Theoretically, it is proposed that the engagement in self-determination practices will lead to increased community-inclusive opportunities and experiences.

Framework Considerations

The framework presented serves as the boundary in which self-determination and community inclusion operate. These parameters include historical, policy, economic, social, and ethical considerations.

Over the past fifty years there have been ongoing efforts to move away from large, segregated, facility-based institutional arrangements of care to providing services and supporting people within the community (DeWeaver, 1983; Lakin and Bruininks, 1985; Bachrach, 1989; Wadsworth, Harper, and McLeran, 1995; Stancliffe and Lankin, 1998). This evolution from institution to community is supported through current public policies such as the Americans with Disabilities Act of 1990 (ADA), as well as through judicial interventions (Parham, Hart, Newton, and Terraciano, 1983; Moss, 1984; Chiles, 1987; Plum, 1987; Holbrook and Percy, 1992; Perlin, 1994; Pfeiffer, 1994; Tower, 1994; Weber, 1994; Henry, Keys, and Jopp, 1996; Mackelprang and Salsgiver, 1996; Huang and Rubin, 1997; Fleischer and Zames, 1998). Economic consideration is central to public policy pursuits as they change the incentive structure for financing service and support systems (Mount, 1990; O'Brian, 1991; Rimmerman, Botuck, and Levy, 1996; Nerney, 1998). Policy is carried out through social efforts and actions. Specific to disabilities, the socialization process may be

hampered as a result of the stigma associated with disability labels (Evens, 1983; Poole, Regoli, and Pogrebin, 1986; Stiles and Kaplan, 1996). Finally, the concept of self-determination itself is subject to ethical tensions between clients and professionals as well as within service and support organizations and communities (Reamer, 1983; Rothman, 1989; Walden, Wolock and Demone, 1990; Fleck-Henderson, 1991; Regehr and Antle, 1997).

Contextual Considerations

Families, interpersonal relationships in the community, service and support organizations, and ordinary places within the community form the context in which self-determination and community inclusion occur. Contextual factors are the set of relationships between people and places that influence the manner in which the concepts play out.

Support-demands on families that include a member with a disability are apparent throughout the family life cycle and are a source of stress (Schreiber, 1984; Lustig, 1996; Lefley, 1997; Seltzer and Heller, 1997). Developing a network within the natural community provides opportunities for people with developmental disabilities to expand supportive, meaningful, and reciprocal relationships beyond their families (Mount and Zwernik (1989; Nisbet, 1992; Mank,

1996; Rogan, 1996). Human service agencies charged with providing supports and services for people with disabilities and their families are faced with developing organizational values and competencies for adopting the philosophies and practices of self-determination and community inclusion (Mount, 1990; O'Brian and Lovett, 1992; Shifting Patterns, 1992; Wolfe, Ofiesh, and Boone, 1996; Henry, Keys, and Balcazar, 1996; Harper, 1996; Smull, 1998). The natural community provides three key ordinary places where individuals are provided opportunities for advancing their citizenship: housing, employment, and school.

Summary

Ultimately, the operalization of self-determination and community inclusion are affected by the framework in which they are contained and the context in which they occur. The relationships between these framework and contextual considerations provide numerous areas for research inquiries. In the sections that follow, the concepts, framework, and contextual factors and forces will be explored in a manner conducive to the development of an integrated research agenda.

CONCEPTUALIZING SELF-DETERMINATION AND COMMUNITY INCLUSION

The concepts of self-determination and community inclusion are unique yet related. Self-determination is described as a set of practices that promote an individual with a disability to assume control and responsibility for life decision-making. Community-inclusive outcomes reflect increased participation in the community by an individual with a disability through developing relationships with ordinary people and natural places in the community. Person-centered planning is a critical conduit to the practices of self-determination and community-inclusive outcomes; it provides for a supportive action-planning environment for people with disabilities.

Self-Determination

Self-determination is examined in two components. First, the origins, definition, and principles of self-determination are presented in order to fully develop the concept. Second, a description of self-determination as related to person-centered planning provides a perspective as to the operalization of the concept.

Self-Determination: Origins, Definition, and Principles

Self-determination originated as a result of the fall of monarchies and the corresponding concerns for freedom and

equality as a concept of political, self-destiny rights of minorities, providing human rights protections and guaranteeing participation of the populace in the political and economic affairs of their nation (Unterberger, 1996; Hurst, 1998). The emergence of self-determination in the disabilities field was first evident in school systems related to school-to-work and community-living transition planning for youths and young adults with disabilities (Hoffman and Field, 1995). Interest in self-determination began to expand as families and advocates professed that processes and practices used with people with disabilities detracted from natural adult life experiences, including making routine daily living choices (O'Connell, 1988; Hoffman and Field, 1995).

Self-determination is fundamentally defined as individuals valuing and knowing themselves resulting in their defining, pursuing, and achieving chosen life ambitions (Hoffman and Field, 1995). Nerney (1998) described the four principles of self-determination as follows:

1. Freedom to develop a personal life plan--the work of those committed to persons with disabilities is simply to assist in operationalizing freedom for those who may need assistance in exercising this basic American right.

2. Authority to control a targeted sum of resources--systems committed to persons with disabilities have to first isolate the dollars available, no matter whether capitation strategies are utilized, and insist that the dollars be under the control of the individuals and freely chosen family and friends. This means that the dollars are also free. They can be re-configured, priorities can be changed, and the dollars can follow the individual.

3. Support to obtain personal goals--those caring individuals who are committed to individuals with disabilities have to also be free to provide assistance both within and without existing systems to achieve the type and intensity of supports that an individual may desire.

4. Responsibility for contributing to one's community and using public dollars wisely--individuals with disabilities and those close to them have the ordinary obligations associated with freedom in America. These are obligations of citizenship and include the obligation to spend public dollars in ways that are life-enhancing and cost-effective. This obligation includes engaging other social, business, and religion organizations in ways that help redefine and build community for all of us. (pp. 5-6)

Although self-determination focuses on what is in the realm of the individual's control, the application of the concept is affected by both internal and external forces: the individual's sense of self as well as the opportunities, choices, and support evident in the environment (Hoffman and Field, 1995).

Central to the concept of self-determination is empowerment: control, choice, and decision-making authority, as well as the free expression of self-advocacy (Wolfe, Ofiesh, and Boone, 1996). Consumer empowerment emerged from the concept of normalization, a concept that was intended to promote community integration; however, it was typically applied in an erroneous manner with a focus on service systems rather than on the individual (Wolfe, Ofiesh, and Boone, 1996). Systems would establish a set of "normal" expectations and impose them through programming efforts directed at the individual while subsequent freedoms were dependent on the person's success in becoming "normal."

Consumer empowerment occurs at both a personal level (self-respect and hope) and collectively (the power of numbers) (Chamberlin, Rogers and Sneed, 1989). Thus, empowerment leads to a sense of self as an individual, the sense of power as a group, and the sense of community. As an example, one community with family teams worked to empower individuals through efforts of reframing community

perspective of people with disabilities. This involved recognizing the talents and gifts of people with disabilities and the resulting investment in the community itself through the inclusion of these individuals (Davidson, Lampman, and Shuman, 1994).

Empowerment is driven by choice. Choice speaks to the freedom of individuals with disabilities to not only decide where they would like to live and work and how they desire to live, but also to make decisions regarding the professionals and para-professionals providing supports and services to them (Allen, 1993). Choice can become problematic when disability-related, traditional, human-service institutions provide few opportunities for persons to make choices. Typically, they only offer a limited array of options (Wolfe, Ofiesh, and Boone, 1996).

Person-Centered Planning and Self-Determination

Self-determination is operationalized through person-centered planning and related practices. Person-centered planning is intended to be ongoing and dynamic in nature, focusing on the individual with the disability as: owning and directing the process through learning and applying capacities, abilities, and opportunities; developing committed relationships; and including ordinary people from the community who can make a difference in an individual's

life (Mount and Zwernik, 1989; Mount and Zwernik, 1994; "Person Centered Planning and Community Action Approaches for Transition to Employment: Concept Paper and Proposals for Possible Pilot Projects," 1995; Hagner, Helm, and Butterworth, 1996). Relationships are defined in terms of individuals with disabilities and their community environment (e.g., social institutions, neighborhoods) as well as their personal systems (e.g., family, friends) (Mount, 1990). These planning efforts bring people, their families, and other significant individuals together as friends, partners, and allies to collectively gain insights and to support the pursuits of lifestyles developed through the individual's preferences, likes, desires, and futures (Mount and Zwernik, 1989; Mount, 1990; Smull and Harrison, 1992; Stineman, Morningstar, Bishop, and Turnball, 1993).

Marrone, Hoff, and Helm (1997) describe the core values of person-centered planning as follows:

1. Driven by the focus individual.

2. Including persons who desire to be supportive of and have a relationship with the individual.

3. Transferring the relationship power from the "helpers" to the person being "helped."

4. Action-oriented.

5. Positive-focused (attributes rather than deficits).

6. Containing dynamic process as opposed to a static meeting.

7. Involving multiple perspectives as a method of expanding creative thinking.

There are a variety of methods to pursue person-centered planning (e.g., Personal Futures Planning, Essential Lifestyles Planning, and McGill Action Planning System [MAPS]). These methods are all bounded by common values and are intended to provide a mechanism for an individual with a disability to play a central role in the planning process (O'Brian and Lovett, 1992; Stineman, Morningstar, Bishop, and Turnball, 1993). These planning methods involve family members, significant others, friends, supporters, and/or acquaintances, typically referred to as a circle of support or circle of friends (Mount, Beeman, and Ducharme, 1988). The circle meets regularly in a natural setting to learn about the individual's ambitions and dreams, and works to remove barriers and to provide support so that she/he may best achieve her/his desired life outcomes (Mount, Beeman, and Ducharme, 1988). Circles provide for safeguards from negative social aspects, opportunities for people to get to know one another and develop friendships, and opportunities to gain interdependent strength in time of crisis and need (Mount, Beeman, and Ducharme, 1988; Pearpoint, 1990).

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Personal Futures Planning is focused on bringing persons together for constructing a relationship map using a person or spokesperson to facilitate the process (Mount, Beeman, and Ducharme, 1988; Amando and Lyon, 1992). That process includes developing an individual profile, identifying dreams and barriers, brainstorming strategies for action, and making commitments to act and continue the process (Mount, Beeman, and Ducharme, 1988). The relationship map describes the daily life and routine of the individual: how she/he spends her/his time as related to inclusive and non-inclusive settings while serving to illustrate potential opportunities (Mount and Zwernik, 1994). The development of the personal profile is an effort to gain an understanding of the individual through her/his hopes, dreams, talents, gifts, relationships, and strengths (Mount and Zwernik, 1989; Amando and Lyon, 1992).

Essential Lifestyles Planning, which heavily emphasizes community participation, frames a desired future of the person by developing a set of efforts and supports required to move toward that future. Supporters must assume responsibility for securing naturally available resources and any additionally needed specialty supports (Vanderccok, York, and Forest, 1989; Mount and Zwernik, 1989). The McGill Action Planning System requires: active contribution and involvement of each individual member of the circle in the

process of developing an understanding of the personal history; defining dreams and nightmares; describing the abilities, talents, and gifts of the focal person; and ultimately organizing this information into a snapshot of the individual's daily routine, defining what the person's ideal day would look like, in order to develop a relevant action plan (Vandercook, York, and Forest, 1989).

The person-centered planning methods presented as examples are practices intended to promote the concept of self-determination. The individual with a disability is the focus. Supporting the individual's positive value of self through the process of planning, pursuing, and achieving outcomes that reflect the individual's desires all serve to advance personal empowerment (Hoffman and Field, 1995). Furthermore, Mount and Zwernik (1994) propose that each of the planning methods described adhere to a planning framework, as follows:

1. Persons involved are committed and have a respect and appreciation for the positive attributes and desires of the individual.

2. There is a collective sense of a positive future and dream that is understood by all.

3. The commitment to congregate and brainstorm is ongoing.

4. At least one person in the group serves as the "champion," taking the lead role in the process of facilitating the dream into reality.

5. At least one community organization serves as a plan implementation-supporting agent.

These planning methods maintain expectations of the participants to assure the implementation as part of their implied promise and commitment and to maintain trust and cohesion in the support circle (Smull, Sanderson, and Harrison, 1996).

Each of the person-centered planning methods is described within a framed set of practices. However, the human element provides a good deal of potential formative problems. Furthermore, an exhaustive review of the literature reveals there are limited person-centered planning related studies conducted.

Hagner, Helm, and Butterworth (1996) conducted a qualitative study to examine the manner in which person-centered planning was being implemented, to determine who participates in these efforts, and to explore the types of plans being developed as well as the effects of the plans. The researchers were particularly interested in the relationships, interactions, roles, and responsibilities of the members of the planning process.

Those who participated in the planning efforts were

categorized as family members, professionals, friends, and a single facilitator. The role of the family members included suggesting inclusive opportunities and providing information regarding natural networks of support, prompting and/or rewording questions as a spokesperson, and advocating on behalf of the individual. The professional's role was defined as being an expert in their particular discipline and technical agent who could remove barriers, seek resources, and generally work through service systems. Friends provided concrete ideas and contributed to the overall plan development and implementation. The facilitator was responsible for the avoidance of negative comments, accurately applying a particular person-centered planning method, ensuring and supporting the active participation and driving force of the individual, moving the planning session along, and encouraging everyone's participation.

The researchers found several key themes as related to equal participation, attitudinal approach, facilitators' adherence to their responsibilities, and the occurrence of positive opportunities that seemingly arose by chance. There were inequalities in the participation of the planning members by age and role and particularly between professionals, who tended to participate more than non-professionals, and family members. Furthermore, the researchers indicated that although the planning was

designed to be positive and driven by the person for whom the planning was being conducted, there was some degree of negativity as well as a shift away from the focus individual. In addition, the facilitators, who sometimes were also serving in the role of professionals, varied in their adherence to the defined set of role expectations. Finally, there were opportunities that simply emerged by chance: members would move quickly on in order to achieve positive outcomes.

The researchers concluded that the planning efforts themselves provided an environment where people could think freely and explore ideas while the professionals became more acquainted with the focal person, which served to change the staff-client relationship and created different and more positive perspectives, opportunities, and efforts. The researchers also stated the importance of family members assuming an advocacy role in response to negativity expressed by the professionals. Finally, the variations found in the application of person-centered planning efforts raised questions regarding the ability to consistently implement these principles and related practices on a systems-wide basis.

Person-centered planning serves as a conduit between self-determination and community inclusion; thus, this process requires an understanding of the role of the

community as related to the contributions of people with disabilities (O'Brian and Lovett, 1992). Facilitators in these planning processes serve as catalysts for enhancing a vision of people and community; as enablers who facilitate rather than direct the process; and as brokers and bridge-builders helping the group to identify resources and make connections to the natural community (Mount, Beeman, and Ducharme, 1988). The clear connection between self-determination and community inclusion revolves around resources, roles, and relationships. Self-determination finds an individual with a disability in control of both financial and support resources; as a valued, contributing member of the natural community; and as continually developing a web of relationships with social institutions, places, groups, and people within the ordinary community.

Community Inclusion

As presented in the previous section, person-centered planning serves as the connecting process between self-determination practices and community-inclusive outcomes. The development of the concept of community inclusion is examined in three elements. First, the concept is described as a set of relationships with ordinary people and natural places in the community. Next, the notion of supporting and accommodating individuals with disabilities is presented as

related to arrangements intended to best assure successful community-inclusive outcomes. Finally, the philosophy and characteristics of community inclusion emerge from the relationship and the support and accommodation considerations.

Relationships with Ordinary People and Natural Places

As the number of persons exiting or never entering facility-based institutional settings continues to increase, the presence of people with disabilities living in the community continues to become more evident (Mount and Zwernik, 1989; Ferguson, 1993). However, as related to a real sense of community inclusion, one study found that, although people with disabilities desired to be included in the community, most were not (Ferguson, 1993). People with disabilities living in a world essentially separate and isolated from the community will lack connections to ordinary and normal personal and public relationships, both casual and intimate. These are the factors that create a valued identification and role of people in general and thereby serve as the context of community inclusion (O'Connell, 1988).

Support and Accommodation

Community inclusion requires a particular perspective in the manner in which supports and services are provided and arranged for people with disabilities. There is a need for flexibility in the design of models and related practices of supports and services in order to promote and successfully achieve opportunities for individuals to be a part of the natural community (Ferguson, 1993; Mount and Zwernik, 1994). These agency and professional practices also need to address the stereotypes that have served to establish barriers to the acceptance of individuals in the community. Finally, these practices need to support opportunities for connections with people and places that occur as individuals assume valued roles in natural community settings and within ordinary relationships across the full spectrum of life domains (O'Connell, 1988; Mount and Zwernik, 1994; McNulty, Connolly, and Wilson, 1996).

Philosophy and Characteristic of Community Inclusion

The philosophy of community inclusion is rooted in individual opportunities for choice, achievements, and satisfaction; in the establishment of continually changing, reciprocal and desired relationships; in the assumption of shared responsibilities to participate and be true to obligations; and in an understanding that, although all

human capacity is unique, all people learn and contribute (Pearpoint, 1993; O'Brian and O'Brian, 1996). The inclusionary concept of "natural community settings" is based on two premises: that people with disabilities grow and flourish best when meaningful real-life activities and tasks take place where they ordinarily occur, using resources one would expect to use in each particular situation; and that there is no substitute for natural environments for problem solving (O'Connell, 1988; Allen, 1993; Harper, 1996).

Peterson (1993) describes the characteristics of community inclusion as supporting the individual, family, and community in a manner that applies:

1. Self-determination principles and practices.
2. Individualized and flexible supports.
3. Quality of life--values and community participation.

Thus in conclusion, community inclusion offers a clear contrast to the concept of exclusion and its segregated, community-based, institutional arrangements and relationships as evidenced in the constraints imposed in specialized residential settings, facility-based work activity programs, special education classrooms versus natural community environments (housing, work, and school settings and arrangements) (Forest and Pearpoint, 1993). In summary, community inclusion is about relationships with

ordinary people and natural places within the community.

Summary of Concepts

Self-determination is derived from the concept of the continued expansion of equality and freedom. At the heart of self-determination are the principles that individuals with disabilities should command life and resource decision-making and that they are valued community members. The choice element of self-determination is a reflection of intended empowerment of the individual.

Person-centered planning serves to operationalize self-determination and is the bridge to community inclusion. Person-centered planning is a dynamic process that includes persons the individual identifies as significant in her/his life, including ordinary people in the community, in a process of developing an action plan to achieve a desired state and future. Although there are a variety of person-centered planning methods, they all share common principles that place the individual with the disability as central in the planning effort and maintain a positive, rather than deficit-based, focus. There is limited person-centered planning related research available and there are questions regarding the ability to systematically apply such an individualized process in order to best evaluate adherence to the model.

Community inclusion is a set of desired outcomes intended to promote relationships between people with disabilities and ordinary members of the community and natural places in the community. This concept includes acknowledgement that people with disabilities may require specialized supports and accommodations. These specialized efforts need to be flexible, reflecting the individual nature of the life pursuits of the person with a disability. The concept maintains that people develop best when they are supported and conduct life activities in natural community environments. Community-inclusive outcomes are pursued through the application of self-determination principles and practices, the use of flexible supports, and a focus on the quality of life of the individual with a disability.

FRAMEWORK OPPORTUNITIES AND CONSTRAINTS

The concepts of self-determination and community inclusion occur within a boundary influenced by history and evolution, public policy, disability economics, social perceptions and related actions, and ethical considerations. Each of these forces provides avenues for opportunities and constraints. For example, the evolution of community inclusion from segregated institutional arrangements to supporting people with disabilities in natural community housing arrangements reflects a parameter that has expanded

over time resulting in increased opportunities. Economics and disabilities provide an example of potential constraints as resources are earmarked toward systems intended on providing supports and services rather than the people with disabilities.

The forces that constitute the framework are explored as they offer insights into the potential influences of the application of self-determination practices and community-inclusive outcomes.

History and Evolution

This section is examined through two perspectives. A brief review of the historical foundation of institutional-based care and treatment is presented. This is followed by a description of the evolution of community inclusion through three distinct eras, initiating with the dependency-oriented philosophy and practices related to segregated community-based care, and emerging with the contemporary values of the interdependent nature of people with disabilities and the natural community.

Institutional-based Care and Treatment

The origins of community inclusion are reflected in historical developments of public policy and social action. Beginning in the mid-19th century, the social and political

response to people with developmental disabilities was anchored in religion, charity, moral obligation, and social exclusionary desire (Galloway, 1980; Tyor and Bell, 1984). People were relegated to large, segregated, facility-based institutional arrangements that evolved through stages of providing schooling, sheltering the individual from society, and protecting society from the person, which in Nazi Germany included the euthanasia of persons with disabilities (Galloway, 1980; Tyor and Bell, 1984; Hollander, 1986; Burleigh, 1991).

Ultimately, states began to reduce the populations, to "deinstitutionalize" facility-based institutions (Dickerson, 1991; Ericson and Mansell, 1996). The three key components of deinstitutionalization are the reduction of large, segregated, facility-based arrangements; the deflection of potential admissions to these facilities; and the movement from single entity, comprehensive service-delivery institutions to multiple entity, community-based service systems (DeWeaver, 1983; Lakin and Bruininks, 1985; Bachrach, 1989; Wadsworth, Harper, and McLeran, 1995; Stancliffe and Lankin, 1998). Financial considerations influenced the institution-to-community movement as both the costs associated with upgrading or replacing aging facilities and the state's ability under Medicaid to cost share and shift to the federal government provided an

economic incentive for this community-based response (Warner, 1989; Braddock, 1992; Buchanan and Alston, 1997).

Emergence of Community Inclusion

The transformation from segregated institutions to integrative communities evolved in three stages. The first generation of community inclusion brought the development of a system of segregated, community-based institutional arrangements that mirrored housing, schooling, employment, and other inclusive opportunities available in the natural community. Practices associated with these segregated arrangements were much like their predecessor: facility-based institutional settings. Disability was viewed as a trait of the individual rather than as an environmental orientation, with services being diagnostically driven and with movement toward increased independence achieved through a service continuum, moving incrementally to less restrictive opportunities and increased freedom (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik, and Stark, 1992; Harper, 1996; Bercovici, 1983). Thus, there was a continued concern with "fixing" the individual through maintaining them in an institutional system that was focused on disability rather than on contributing to the building of a natural community experience (O'Connell, 1988; Pearpoint, 1990).

With continued pressure from advocates for greater integration, the second generation of community inclusion found movement from the segregated, continuum-based specialized service-delivery design to an array of flexible and individualized supports (e.g., natural community settings of housing, schools, and jobs)—(Goldberg, McLean, LaVigne, Fratolillo, and Sullivan, 1990; Henry, Keys, and Balcazar, 1996). The process of community involvement (opportunities for a more typical lifestyle and valued role) was intended to promote increased citizenship, to diminish the adverse social perception of differences which originated from the days of facility-based institutional care, and to advance a more positive political and social perspective regarding people with developmental disabilities (Wolfensberger, 1983; O'Connell, 1988).

Contemporary theory and practice constitute the third generation of community inclusion, extending beyond the one-dimensional physical aspect of community integration toward full inclusion. At the core of true inclusion are people. True inclusion indicates a network of relationships with other community members forged as lasting and reciprocal, anchored on mutual respect, and intended to enhance the quality of life for both individuals with disabilities and persons who do not have a disability (Mount, Beeman and Ducharme, 1988; Perske and Perske, 1988; O'Connell, 1988;

Amando, Conklin, and Wells, 1990; Sullivan, 1992). The concept of community building through the development of meaningful relationships has expanded beyond the physical places aspect of inclusion to opportunities to meet and become acquainted with people and develop potential friendships (Amando, Conklin, and Wells, 1990).

Disability Rights Policy Initiatives

This evolutionary path forged by the disabilities rights and consumerism movements over the second half of the 1900s has promoted concepts and legal rights such as social inclusion, mainstreaming, normalization, housing and employment access, accommodation, and least restrictive environments as manifest in federal legislation and judicial interventions (Parham, Hart, Newton, and Terraciano, 1983; Moss, 1984; Chiles, 1987; Plum, 1987; Holbrook and Percy, 1992; Perlin, 1994; Pfeiffer, 1993; Tower, 1994; Weber, 1994; Henry, Keys, and Jopp, 1996; Mackelprang and Salsgiver, 1996; Huang and Rubin, 1997; Fleischer and Zames, 1998). Four key public policies consistent with these concepts that have been enacted are the Americans with Disabilities Act of 1990, the Individuals with Disabilities Education Act of 1990, the Rehabilitation Act of 1973, and the Developmental Disabilities Act of 1984 (all four, as amended).

The Americans with Disabilities Act (ADA) provides for legal rights promoting increased inclusive opportunities for people with disabilities in natural settings (Wolfe, Ofiesh, and Boone, 1996; Pfeiffer, 1993; Fleischer and Zames, 1998). The Individuals with Disabilities Education Act (IDEA) requires full and earnest efforts for children and youth with disabilities to be provided an education in the same setting and manner as their peers who do not have disabilities, as well as developing school-to-community transition plans to ready youths for young adulthood (Hoffman and Field, 1995; 20 USC 1412(5)(B) as cited in McNulty, Connolly, and Wilson, 1996). The Rehabilitation Act, which mirrors the definitions and provisions of IDEA, supports self-determination practices by recognizing that people with disabilities have the right to make choices and to be a part of the natural community as contributors in all aspects of community life (Chiles, 1987; Weber, 1994; Hoffman and Field, 1995). The Developmental Disability Act includes a definition of supporting persons with disabilities in paid employment (Simmons and Flexer, 1992).

All of these policy initiatives are consistent with the "people first" philosophy which recognizes that a person's best interests are represented through the expression of his/her own choices and desires and the recognition of his/her citizenship with the right to be part of an

inclusive community (McGrath and Grant, 1992; Shifting Patterns, 1992; Hoyle and Kloc, 1995). Although these policy initiatives legally support the notion of self-determination and community inclusion, the achievement of the anticipated values, practices, and outcomes through mandates have been problematic. In a study of a state's efforts to prepare people with disabilities to understand and act on their rights under the ADA, the findings reflected that only a small number of responding service providers thought there was a need to provide choice and decision-making opportunities and community integration for people with disabilities (Wolfe, Ofiesh, and Boone, 1996). In education, the problem has led to a continuing concern that litigation will serve as the primary method for implementing equal and inclusive schooling until real inclusive opportunities are provided to youths with disabilities (McNulty, Connolly, and Wilson, 1996).

Disabilities and Economics

Public policy is defined through the structuring and allocation of economic resources. The obstacles of poverty potentially challenge ultimate access to the mainstream of natural community resources and processes. In shifting to person-centered practices of developing community-inclusive futures for individuals with disabilities, poverty becomes a

critical point of tension, seemingly offering only fixed and limited resources resulting in potential shortcomings in inclusive opportunities and personal self-worth concerns (Mount, 1990; Rimmerman, Botuck, and Levy, 1996).

Finance policy has directed resources to human service systems rather than to individuals with disabilities. People with disabilities lack a sufficient disposable income necessary in resource-acquisition and relationship-building with the natural community. This financing of systems rather than people has served to reinforce the implications of the unilateral and structural nature of the impoverished state of people with disabilities (O'Brien, 1991; Nerney, 1998). Furthermore, people with disabilities may be most valued as a means of generating financial resources for the systems designed to provide them with supports and services, while these systems may very well fear the adverse effects that may occur as a result of increased real empowerment of individuals with disabilities (Mount, 1992; Wolfe, Ofiesh, and Boone, 1996). Pervasive poverty of people with developmental disabilities and their acquiring command of the financial resources used to provide supports and services would seem to be critical considerations relative to the adequacy and accuracy of self-determination practices (Nerney, 1998).

Disabilities and Society

Kilbury, Benshoff, and Rubin (1992) examine the successful application of disability policies through the circular relationship among social attitudes, the policies themselves, community accessibility, and social interaction. As an example, the ideological assumptions of deinstitutionalization, including the acceptance of people with disabilities into ways and means of natural community life, in reality clash with actual social behaviors (Asch, 1986; Shadish, Lurigio, and Lewis, 1989; Arens, 1993). The "Not in my Backyard" (NIMBY) phenomenon (community opposition to group homes for people with disabilities) offers a concrete example of the conflict between public policy ideology and social implementation.

In a study of neighborhood desirability regarding community placement of people with disabilities, researchers found that the number of supporters outweighed those opposed by a two-to-one margin (Currie, Trute, Tefft, and Segall, 1989). However, several other investigations provide a perspective regarding active opposition. Hogan (1986) examined political mobilization of neighborhood forces opposed to group homes and surmised that, prior to purchase or rental terms being reached, influence to block the development of homes experienced some successes in efforts to persuade the owner not to sell or rent the home. These

findings suggest accessibility to community housing may be denied prior to community members actually meeting the individuals who may potentially become their new neighbors. Constituent characteristics, as related to the political power of influencing local elected officials as well as conflicting research regarding the economic effect (as adverse or benign) of dwellings for people with disabilities on surrounding neighborhood property values, lead to actions opposing the development of group homes (Farber, 1986; Graham and Hogan, 1990; Clingermayer, 1994; Galster and Williams, 1994).

Stigma and labeling may offer insights regarding social attitudes toward people with disabilities. Social stigma as defined, occurs when as a group of individuals are vulnerable to prejudice or discrimination, or are viewed as deviant (Crocker and Major, 1989). Stigma is then manifested in the images and associations attributed to the group. For example, people with disabilities depicted by the media have presented images and messages ranging from criminal associations to pity (Longmore, 1985). The media is recognized as such a vital force that in the process of pursuing the passage of the ADA, disability advocates minimized the use of press coverage in promoting the passage of the act, citing the media as an impediment (Shapiro, 1994). Relative to potentially negative social consequences,

in a study of initial developmental disabilities diagnosis, Gill and Maynard (1995) concluded that professionals proceeded with a great deal of caution in these discussions with parents.

Galloway (1980) argues that labeling people as devalued and comparatively "different" from the general populace has contributed to perceptions that ultimately legitimize negative stereotypes, encourages the abandonment of human and citizen rights, and advances the process of brutalization. O'Connell (1988) further describes the process of simply branding people with disability labels and discounting their humanity as contributing to isolation from the natural community while segregating individuals into a system of service-delivery, care, and treatment maintained within a web of community-based institutional arrangements and practices. Even people who themselves are labeled may act and portray themselves in ways that reinforce negative actions and attitudes relative to the label (Evens, 1983; Poole, Regoli, and Pogrebin, 1986; Stiles and Kaplan, 1996). Furthermore, awareness of socially stigmatizing attitudes and behaviors lead to ambivalence of self, psychological pain, and an overall diminished quality of life (Stager, Chassin and Young, 1983; Szivos and Travers, 1988; Levy, 1993; Reiss and Benson, 1994; Blaine, Crocker and Major, 1995; Dudley, 1997; Rosenfield, 1997). Finally,

stigma-related attitudes relative to mental retardation may contribute to the diminished perceptions by professionals of the individual's competencies and ability to express desires and needs (Dudley, 1987).

Absolute assumptions that all attitudes and actions can be categorized as negative relative to people with disabilities are inaccurate. In a study of public kindness toward people using wheelchairs, Cahill and Eggleston (1995) found that the complexities of actions created problems with simply identifying them as positive or negative. Additionally, assumptions that negative stigmas cannot be reversed are also not fully supported. In an experimental effort examining the effects of a learning intervention structured as cooperative contact and equal status, researchers found that initial, negative expectations of the stereotyped individual with a disability by an individual who did not have a disability would move through an adjustment stage during the learning effort and ultimately reach a point where positive generalizations were formed (Desforges, Lord, Ramsey, Mason, Van Leeuwen, West, and Lepper, 1991).

In an attempt to counteract stigma, initial efforts of supporting persons in the community and concerns regarding rights of full citizenship were framed within the principle of normalization (Lerman, 1985; Landesman and Butterfield,

1987). The concept of normalization involved the use of socially-valued roles and life conditions that convey the image, characteristics, and support of an individual in a manner that is culturally normative (Wolfensberger, 1980; Gardner and Chapman, 1993; Sinson, 1993). The concept of normalization was intended to move away from the social categorization of people with disabilities as a subordinate culture which, in turn, created social distance (Ferguson, 1987; Mbilinyi, 1993). Critics argue that, although intended to promote a socially-valued role, the concept of normalization detracted from personal individuality and autonomy (Rose-Ackerman, 1982; Phillips, 1985). For example, an individual may desire to make a decision that, if carried out, would not reflect a culturally-normative practice or socially-valued outcome.

Ethics and Self-Determination

The concept of self-determination addresses the individual autonomy limitation inherent within the principles of normalization. With a commitment to self-direction and individual freedom comes critical ethical dilemmas. Central to the conflict is the delicate balance between the inherent rights of the individual and compelling social interests. At the same time, interdependent relationships and legal influences require consideration and

critical understanding.

Variation in life experiences and information influence individual choices that, in turn, could reasonably cause harm to an individual and/or others. Individual choices present challenges to anyone, particularly professionals, in supporting self-determination (Reamer, 1983; Rothman, 1989; Regehr and Antle, 1997). Interventions in these situations could be paternalistic in nature; that is, the professional may act in the "best interest" of the individual with a disability even though said action is not consistent with the individual's desires (Abramson, 1996). Furthermore, in the event an individual's competency comes into question, a legal guardian may be secured. In these instances, the autonomy of an individual is diminished in favor of substitute judgement by the guardian, potentially even beyond the scope of the guardianship (Stebnicki, 1994). Additionally, supporting professionals are confronted with needing to understand choices and actions of a person relative to the uniqueness of the individual within the context of her/his culture and social reference group, including other individuals with disabilities (Holland and Kilpatrick, 1991; Ewalt and Mokuau, 1995).

Professional ethical considerations have been shown to be key in the practice of supporting the self-determination and community inclusion of people with disabilities. The

literature of the social work profession offers an example of the fundamental issues concerning relationships between individuals, professionals, and collective values and the resulting ethical tensions and dilemmas.

Much like the evolution of institutional care, social work ethics have evolved from a concern with the morality of clients to a contemporary focus on ethics as related to self, the profession, and practice (Reamer, 1998). An ethical sense of self is developed through ongoing personal evaluation; through experiences, approaches, and dialogue related to concurring and conflicting social values and practice efforts (Abramson, 1996; Siporin, 1982). This ethical awareness is critical in practice as it provides an understanding of self in an emphatic relationship with a client with different values, and it serves as the premise for making clinical decisions in light of moral dilemmas (Woddy, 1990; Dean and Rhodes, 1992; Rhodes, 1992). In addition to individual client values, the employer organization is yet another arena for ethical tensions in decision-making by professionals (Walden, Wolock and Demone, 1990; Fleck-Henderson, 1991).

Human sexuality of individuals with disabilities offers an optimal example of the complexity and multitude of ethical concerns. Linzer (1992) and Howard, Lipsitz, Shepard, and Steiniz (1991) provide an analysis of a case

study involving a sectarian agency in its efforts to design an organizational policy regarding the sexual behaviors of residents with disabilities in its residential programs. The organization's ethics committee evaluated this issue as it related to the individual client, agency purpose, professional ethics, community values, family perspectives, religious beliefs, and public sector regulations. The resultant policy required that the organization provide education, guidance, and counseling (by staff) as necessary and appropriate; permit sexual expression on an individual basis as related to needs, values, desires, and competencies (as determined along with the professionals); and prohibit sexual intercourse on the provider's property for non-married individuals.

Summary of Framework

Until the second half of the twentieth century individuals with developmental disabilities were served in large, segregated, facility-based arrangements. Within these settings, practices ranged from reflecting the need to protect these individuals from society to protecting society from these persons. Over the past fifty years, the philosophy and practice of serving and supporting individuals with developmental disabilities has evolved through three distinct stages. The initial era was

dependency-oriented and involved segregation in the community. The second era was independence-oriented and provided for institutional-like practices in the community. The contemporary era seemingly is consistent with self-determination practices and community-inclusive outcomes as it acknowledges the interdependent nature of people with developmental disabilities and the role and relationship of the natural community. Public policy, such as the Americans with Disability Act, supports the citizen rights focus inherent in self-determination.

Although public policy could be argued as a set of mandated provisions intended on increasing self-determination and community-inclusive opportunities for people with developmental disabilities, economic factors pose potential constraints. Finance policy directs resources to systems intended to provide services and supports for individuals with developmental disabilities while the people themselves are impoverished. This is a particular challenge to the principle of the individual controlling resources and related decision-making as it could be argued that these resources are the "property" of the support organizations. Additionally, from a community inclusion perspective, provider organizations could lobby for continued funding of specialized systems of care, therefore diminishing the financial resources available for implementing a community

capacity-building strategy of pursuing supported arrangements (e.g., living and work) in the natural community.

Social forces may also serve as a constraint in self-determination and community inclusion efforts. Stigmas resulting from perceptions, images, and disability labels influence communities, organizations, professionals, and families as well as people with developmental disabilities. Acting on stigmas may result in minimizing an individual's competencies to engage in self-determination practices and to develop relationships in the natural community. Professional ethical considerations may also serve to limit choice and empowerment of people with developmental disabilities. The concept of self-determination itself raises a continual professional ethical dilemma associated with supporting freedom, acting in substitute judgement, acting in the best interest, and not supporting the decisions of individuals with developmental disabilities relative to each unique circumstance and situation that presents.

CONTEXTUAL FORCES

The framework components provide for the arena in which self-determination and community inclusion unfolds. The contextual forces relate to the influences within this

parameter. Family, community, and organizational systems are contextual considerations presented in the following sections. Housing, employment, and educational models of support practice are also described. These models of practice provide a substantive illustration of the role of contextual forces in supporting people with developmental disabilities in natural community settings.

Family Systems

Family systems encounter crises in life cycle transitions, such as when children go off to college or get married. These normative transitions are confounded in families with members with disabilities (Schreiber, 1984; Lustig, 1996). Families are faced with real or perceived social rejection related to the disability label and may feel they will only find answers through structured programs (O'Connell, 1988). Concrete concerns, such as financial resources, are also a source of stress. For example, Arnold and Case (1993) conducted a study of the needs of families who were providing care for a relative with a disability and found a relationship between diminished financial resources of the family and the expressed need for health care, employment, and financial subsidies.

Throughout the life cycle, families are reported to be faced with developing coping and support mechanisms related

to family member relationships, caregiving burdens, out-of-home placement, and maneuverability through the service and support systems. These life cycle challenges are presented in the sections below.

Coping, Support, and Adjustments

Family adjustments and reactions occur within and between each family member as well as in external relationships. A research effort by Floyd and Zimich (1991) in co-parenting interactions found a relationship between diminished marital satisfaction by both parents and more severe behaviors exhibited by the child. In a study of family relationships and marital quality of mothers of a child with a disability, findings included a multivariate relationship between diminished depression and increased satisfaction with their marriage, and the existence of a support network (Friedrich, Cohen, and Wilturner, 1987). Social supports appear to provide an avenue for parents to maintain strength during those times when their ability to cope with the demands of caring for their child is diminished (Schilling, Gilchrist, and Schinke, 1984).

In a study examining the strengths of parents with a child with mental retardation, Abbott and Meridith (1986) reported that the experience had drawn families closer together and that coping was best achieved through the

maintenance of a positive approach to the circumstances. However, generalizations between mothers and fathers regarding the role of coping strategies and parenting may be problematic. In a study comparing the involvement of mothers and fathers in programs for their children, one finding, while controlling for financial security and education, indicated that parental involvement of mothers was enhanced with the application of a family problem-resolution coping mechanism while involvement of fathers was not related to such coping strategies (Gavidia-Payne and Stoneman, 1997). This research suggests that fathers may be more inhibited in seeking resolution to problems within the family structure as compared to mothers.

Caregiving Burden and Satisfaction

The literature is consistent in demonstrating that caregiving demands of a child or adult child with a disability is a key contributor to family stress. The depth and breadth of caregiving throughout the life cycle may vary relative to contextual factors including the characteristics of the family and the nature of the family member's disability (Lefley, 1997; Seltzer and Heller, 1997). In a study of families conducted in the Netherlands, researchers reported a relationship between the type and severity of disability and functioning level and the intensity of

caregiving demands, with the response adequacy of the service system being a mitigating factor (Haveman, van Berkum, Reijnders, and Heller, 1997). In a study of variation in caregiving demands across the lifespan between mothers and fathers, researchers found that the caregiving tasks and perceptions were greatest for the mother, particularly if the offspring lived in the home (Heller, Hsieh, and Rowitz, 1997).

The mother as the primary caregiver, including general parental involvement, is evident throughout the literature. Konstantareas and Homatidis (1992) conducted a study comparing home parental involvement of three groups of mothers and fathers (autistic child, mentally-delayed child, and normal child). Although they found differences among each group, parents of autistic children being least involved, and parents of normal children being most involved, fathers were involved less than mothers in all three groups.

Co-parenting, socio-culture considerations, sibling interaction and involvement, and age all contribute to the caregiving stress of mothers. Marcenko and Meyers (1991) presented findings of a study in which married mothers reported more caregiving help from the father and his family than did non-married mothers. One element of a study on employment and single mothers of children with developmental

disabilities found that mothers employed full-time serving as the primary source of income experienced greater stress, depression, and health concerns as compared to mothers whose work income was not their primary source of support, even if their overall income was comparatively less (Gottlieb, 1997). Gottlieb (1997) also found that the existence of a supportive partner and the fulfillment of multiple roles served to enhance a mother's life.

Pruchno, Patrick, and Burant (1997) conducted a comparative study between African-American and white mothers of adults with chronic disabilities, examining caregiving burden and satisfaction. They found that African American mothers reported greater caregiving satisfaction and less burden than the white mothers, even though they had lower incomes, education, and were more likely unmarried. In a study of culture and family caregiving, one key finding involved the identification of barriers present related to overall access of services and supports resulting from cultural competency shortcomings of the human service system (McCallion, Janicki, and Grant-Griffin; 1997).

In a study comparing the relationships between siblings in families of a child with a disability and families where no child had a disability, it was found there was no difference in the amount of time spent between siblings; however, the brothers and sisters of a sibling with a

disability spent more time in caregiving efforts (McHale and Gamble, 1989; McHale and Pawletko, 1992). Auletta and DeRosa (1991) conducted a comparative analysis of self-concepts of adolescents who had siblings with disabilities and those who did not have siblings with disabilities, and found no significant difference between the two groups.

In a research effort examining sibling involvement in caregiving, Seltzer, Begun, Selzer, and Krauss (1991) found that the well-being (physical health, life satisfaction, burden, and stress) of aging mothers was comparatively better in those instances where siblings were involved in caregiving as compared to mothers who had no other children or where the siblings were not involved in caregiving. In a study of aging mothers and their adult children with chronic disabilities, researchers reported that although the relationship between siblings with no disabilities and siblings with disabilities were strong, they did not provide much in the way of caregiving (Pruchno, Patrick, and Burant, 1996). A source of family stress for aging parents of adult children with disabilities is the concern of caregiving following their deaths (Mengal, Marcus and Dunkle, 1996). Griffiths and Unger (1994) examined paired parents and siblings regarding their future planning perspectives for their family member with mental retardation and found just under one quarter of the parents identified the expectation

of long-term caregiving as becoming a responsibility of their adult children, with a daughter being identified as the future caregiver in these instances.

Greenberg, Seltzer, and Greenley (1993) found that aging mothers of adult children with mental retardation had increased caregiver stress relative to greater amounts of direct care being provided. Even if an adult child moves out of the home, mothers may exhibit other psychological problems. Selzer, Greenberg, Krauss, Wyngaarden, and Hong (1997) studied outcomes of aging mothers of adult children with mental retardation and aging mothers of children with mental illness and found that both groups exhibited continued depressive symptoms following the adult child moving out of the home and the mother relinquishing her caregiving role.

Positive attributes of mothers may serve to mitigate the adverse psychological aspects of caregiving. In an examination of two different late life challenges, researchers conducted a comparative study between mothers experiencing home relocation and mothers responsible for caregiving for their adult child with mental retardation and rendered two key findings: the relocating mothers reported more positive well-being while the caregiving mothers reported a greater sense of purpose with their lives (Kling, Seltzer, and Ryff, 1997). Smith (1996) described positive

psychological well-being (satisfaction with their lives) reported by older mothers of adults with mental retardation as contributing to diminished subjective caregiving burden (feelings related to the presence of their son or daughter).

Changes in Living Arrangements

It has been suggested that the movement of individuals from institutional settings to the community, as well as within the community, contributes to stress within the family unit (Sherman and Cocozza, 1984). Adjustments to deinstitutionalization include parents being confronted with confusion related to professionals informing them to set aside the care assurances provided at the initial time of institutionalization in favor of new service and support guarantees now being made in the community (Ursprung, 1984).

While movement out of the home may itself be a source of stress, there is research that suggests families may respond and adjust in a manner similar to what might be anticipated with activities associated with a child with no disability. In a longitudinal research effort regarding family involvement with children after placement in a residential treatment program, findings supported the notion that families did not detach; their involvement remained high and constant (Blacher and Baker, 1994). Blacher and Baker (1994) found that family decisions regarding placement

typically followed increased stress related to the child with the disability, and that the families were satisfied with the placements and the adaptation of the family post placement. In an investigation of sibling adjustment relative to placements of children with disabilities outside of the home as compared to children who remained in the home, subjects reported a concern with the potential for diminished strength of family relationships if a placement occurred, whereas the placement group reported that these relationships stayed the same or improved (Eisenberg, Baker and Blacher; 1998).

Families and Support and Service Policies and Systems

Contributions to and alleviation of family stress can be derived from the policies and systems designed to provide specialty services and supports. In a study of family stress and the need for services involving families on waiting lists for services, Hayden and Goldman (1996) found a significant relationship between increased number of services needed and greater family stress. In a multifaceted study of parental stress, caregiving, and service utilization, Floyd and Gallagher (1997) reported a key finding that single mothers, although not more stressed, used more services in comparison to married mothers.

Zimmerman (1984) completed a study of the Family

Subsidy Program for families with a child with mental retardation and found that the program was achieving its intended outcomes. Families were satisfied and their coping abilities improved with the use of flexible funds in the purchase of such services as respite care and other items for supporting their child. Families were also concerned with the individuals who deliver services as well as with process issues such as planning. In a study of quality of services, one finding was that while families ranked the qualifications of family support workers as very important, professional coordinators were more concerned with worker attitude (Marcenko, Herman, and Hazel, 1992). In addition, the subjects consistently ranked fifteen quality factors as important, including empowerment, accessibility, advocacy, and family focus.

Family Systems Summary

Families with a child/adult with a disability are faced with numerous challenges throughout the life cycle. Social support networks are intended to contribute to positive family coping and adjustment. Family characteristics, such as marital and financial status, create variations in caregiver demands. It is apparent that mothers assume a greater amount of demands in comparison to fathers in caregiving for a child/adult with a developmental

disability. Mothers were found to be more involved with problem-solving responsibilities and as caregiver. This gender consideration extended to daughters who were more likely than sons to be identified as future caregivers after the death of the mother. Satisfaction with her life in general and having a supportive partner were identified as factors that diminished caregiving stress of mothers.

Out-of-home placement appears to have limited adverse effect on the relationship between families and the member with a disability. Post placement relationships between the family member with a disability and her/his family remained the same or grew stronger.

The responsiveness of the service system mitigates some caregiving demands. The flexible funds provided by the Family Subsidy program was identified as contributing to the coping abilities of families. The concept of families desiring responsiveness in service systems was evident in the emphasis being placed on advocacy and empowerment practices and accessibility of the service system.

Community Support and Relationship Systems

Supported living, supported employment, and inclusive education are models of inclusive practices across three very critical life domains. These domains are places in the community intended to provide individuals with opportunities

to express their freedom, socially gain value, develop and enhance meaningful competencies, and gain resources available to everyone in the community. Central to all three of these models is the concept of support. Support provided by responsible human service systems is intended to be made available in the event it is not ordinarily available in the community as well as to augment natural community supports. Thus, in further developing the concept of community inclusion, consideration must be given to natural supports and relationship networks.

Natural Supports and Ordinary Relationships

Although self-determination and community inclusion are unique and individual concepts, natural supports as a construct is present in both (Test and Wood, 1996). The definition of natural supports is somewhat lacking as are empirical studies in this regard; however, these limitations serve to allow for a definition to emerge through exploratory study (Test and Wood, 1996, Mank, 1996).

As a concept, natural supports are described as a phenomenon of providing and reciprocating social support which may occur spontaneously in the natural environment or result from interventions, including those of human service organizations (Hagner, and DiLeo, 1993; Butterworth, Hagner, Kiernan and Schalock, 1996). Among other functions, natural

supports are intended to promote increased inclusive outcomes. They require a commitment to the value that individuals with disabilities can form meaningful relationships and that they can develop skills in strategies related to the development of a natural support system (Nisbet, 1992; Mank, 1996; Rogan, 1996). Natural supports are modified, typically through natural processes, as needs change; they are not used as a method of reducing the costs of responsible human service systems (Rogan, 1996; Trach and Mayhall, 1997).

Strategies associated with natural supports involve the application of resources and practices that facilitate integrative, naturally-driven supports and accommodations for people with disabilities in a manner consistent with the intentions and valued opportunities available in the environment: for example, children with no disability who become mentors for children with disabilities ("Shifting Patterns," 1992; Butterworth, Hagner, Kiernan, and Schalock, 1996). It is noted that support needs, as well as natural support network composition and numbers, may continuously change through time; thus external supports provided by responsible human services systems may be required periodically or permanently and with variation in type, scope, and intensity (Butterworth, Hagner, Kiernan and Schalock, 1996).

Social Relationship Networks

Natural supports form a web that constitutes a relationship network. Mount and Zwernik (1989) identified seven principles in the conceptualization of networks, as follows:

1. Networks often form around two people who are in a very strong relationship where one is an advocate who speaks for the person with the disability.
2. Strong networks usually form around a person who really wants to change.
3. The person who is the focus of the network will grow in direct relationship to the honesty and commitment of the network members.
4. The purpose and direction of the network is defined by the focus person's dream.
5. The size of the network depends on how much the focus person wants to change and how fast.
6. Networks often come into being during a crisis.
7. A facilitator may be needed to help form a network when the group seems stuck. (pp. 28-29)

As described in the principles presented above, the values of person-centered planning parallel the concept of networks, while networks facilitate community inclusion. Person-centered planning is individual in nature and

involves the individual with the disability as the focus in a network of persons who she/he identifies as significant in her/his life. Involvement of these ordinary community member network actors is intended to open new avenues to natural community-inclusive experiences.

Life Experience and Community Inclusion

Encouragement is necessary for individuals who lack life experiences within the context of the natural community as a result of having lived in virtual isolation (Amando, Conklin, and Wells, 1990). The protective image and practices, in tandem with the failure of the human service systems responsible for providing supports and services to be attentive to relationships, also function as real inclusion (Amando, Conklin, and Wells, 1990). Supporting an individual with a disability requires the acceptance that there will be imperfections, rejections in relationships, and failures in friendships; however, the emergence of the person as a socially-dignified and valued member of the community will not occur until she/he develops a sense of self, largely defined through meaningful relationships with both places in the natural community and with the people who constitute the community itself (O'Connell, 1988; O'Brien, 1991).

Community Bridge Building serves as a model to link

people with disabilities and other community members through inquiry of what is important to each party and then determining how they would like to pursue it together (O'Brian and O'Brian, 1996). Bridge Building is a value as well as a practice, and it is used as a method of actively promoting community-inclusive opportunities through the direct coupling of people with disabilities and other community members (Mount, Beeman, and Ducharme, 1988). In applying person-centered practices, Bridge Building is also focused on the relationship between individuals with disabilities, the community, and responsible human service systems as well as advocacy efforts to reshape human service systems so that people can better be supported in their own homes, in real jobs, and in meaningful relationships in the community (Mount, Beeman, and Ducharme, 1988).

Community Support and Relationships Systems Summary

The interdependent concept of support is central to the application of models of practice intended on promoting community-inclusive outcomes. Specialized support and accommodation is intended to augment what is not available naturally in the community. Natural supports are defined as reciprocal relationships involving ordinary people and natural places in the community. People with developmental disabilities are presumed to be competent in developing

meaningful relationships. These meaningful relationships with natural supports merge into an overall support network for people with disabilities. The person-centered planning process is intended to be conducive for responding to the continuously changing mix of natural and specialized supports as well as addressing problems associated with an individual's life experience of isolation and the corresponding need for encouragement and support to explore new opportunities.

Organization Systems

Local human service organizations are faced with three management functions: program (administration and operations), resource (creation of an administrative structure), and policy (resource mobilization and allocation, strategizing, planning and prioritization) (Castellani, 1992). This new era of "deinstitutionalization" as related to the concepts of self-determination and community inclusion will require strategies to assure that organizational design and practices meet the demands of policy initiatives. For example, in an evaluation of the state of New York's deinstitutionalization efforts, local organizations' capacity relative to the policy management function were challenged beyond their limits and failed to adequately support the transference to the community

(Castellani, 1992).

Rehabilitation, school, social service, and mental health organizations are the key human service systems responsible for providing and/or arranging supports and services for individuals with developmental disabilities and their families. Supports are defined as both naturally available (people and places in the community who routinely provide the services that are needed as well as the desired involvement of families and friends) and intentionally provided (paid community support aids as well as disability-related technological adaptations and environmental modifications). It is held as a critical value that supports are to be as natural and non-intrusive as possible (Butterworth, Whitney-Thomas, and Shaw, 1997). For example, supported employment practice requires the examination of the environment for natural supports and/or financially-compensating community resources to provide natural supports before using specialized supports (Peterson, 1995; Trach and Mayhall, 1997).

Change Strategies

Policy and practice initiatives find systems moving in response to the legal rights of people with disabilities to be included as participants in the community (Wolfe, Ofiesh, and Boone, 1996). These organizations, as a collective

system as well as a set of individual entities, would need to apply strategies consistent with consumer empowerment, self-determination, and support-oriented models of practice as they move toward offering an array of supports and services rather than a service continuum (Mount, 1990; O'Brian and Lovett, 1992; Shifting Patterns, 1992; Wolfe, Ofiesh, and Boone, 1996; Henry, Keys, and Balcazar, 1996; Harper, 1996; Smull, 1998). From a disabilities rights perspective, responses to people with disabilities include coordinating supports around the life of the person as opposed to the needs of staff or programs, and using resources in the community rather than creating segregated arrangements that mirror what is available naturally (Mount and Zwernik, 1989; O'Brian and Lovett, 1992).

Self-determination driven person-centered planning is a process that is unlike traditional, professional treatment teams and agency-centered planning (Mount, Beeman, and Ducharme, 1988; Shifting Patterns, 1992; Hagner, Helm, and Butterworth, 1996). These planning practices represent a philosophical shift requiring professionals to give up control and make a commitment to the values and desires of the individual (O'Connell, 1988; Hagner, Helm, and Butterworth, 1996; Wolf-Branigin, 1997). Community-inclusive outcomes derived from person-centered planning require innovations such as support and response models of practice

based on community capacity-building, including supporting people in the development of individual friendships (Mount, Beeman, and Ducharme, 1988; Mount, 1990; Amando, Conklin, and Wells, 1990; Mount and Zwernik, 1994).

A critical component of self-determination involves individuals having command of resources as well as advancing their own economic well-being. Individual Support Plans (ISP) that emerge from person-centered planning efforts include the identification of human, adaptive, technical, and financial resource needs. In this process, the use of vouchers allow individuals to directly express their choice through decisions made in purchasing supports and services (Shifting Patterns, 1992; Nerney, 1998). The use of vouchers introduces consumer purchase options that create systems based on customer-service, competition, and the need to expand organizational roles into the area of fiscal intermediator. This model includes provisions that individuals hire and fire their community support staff (para-professionals providing direct support) as well as professionals providing specific clinical or case management/support coordination-type services (O'Brien, 1991). Controlling resources includes supporting individuals with disabilities in efforts to gain financial and personal security, particularly as related to becoming owners or tenants in homes in the community rather than living in

residential programs where they have no legal right of occupancy (O'Brien, 1991; Smull, 1998).

Organization Quality, Characteristics, and Leadership

Concerns with quality are evident in human service organizations, particularly as related to best practice and the advancement of managed care and accreditation. Person-centered planning is consistent with the fundamental principle of quality as both are concerned with attention to the preferences of the consumer and achieving related outcomes (Sashkin and Kiser, 1993; Gardner, Nudler, and Chapman, 1997). Gardner, Nudler, and Chapman (1997) describe the Council on Quality Leadership accreditation standards as including the following:

1. The principle that consumers define outcomes through experiences derived from an array of options and the organization facilitates the pursuit of those options.

2. Dimensions that include examining people being given options to choose from and provided support in learning through experiences, while families and professionals exercise creativity in identifying a variety of choices.

3. The measurement of personal goals--where people live, where they work, how they use free time, choice of services, daily routine, life in the community, relationships, rights, safe and integrated environments,

economic resources, and satisfaction.

Furthermore, defining quality, as quality of life and as evidenced through person-centered planning, is unique in nature; variations are found in what each individual defines as "good" and "bad" quality (Taylor and Bogdan, 1990; Mount, 1992; O'Brien and Lovett, 1992).

As related to quality considerations, the literature revealed several examples of key human-service system characteristics that are worth examining. Case managers have been burdened with paperwork requirements, the need to satisfy regulations, and very limited authority while the model itself serves primarily as a mechanism to allow access to programs offered within the service delivery system (Shifting Patterns, 1992; Smull, 1998). Private business has not been actively involved in organizational and community supported employment planning efforts. For example, rehabilitation systems' employment strategies reflect internally-driven interests in process and individual financial concerns which have been incompatible with the external business interest in performance and profit (Drucker, 1985; Moxley and Visingardi, 1988; Simmons and Flexer, 1992). Formal teacher training and educational systems have not prepared teachers to work with diverse children and youths with disabilities (Villa, Thousand, and Chapple, 1996). Indeed it has been argued that traditional

practices, which have systematically failed to support valued real-life outcomes focused and based on the desires of individuals with disabilities, reflected power misplaced in the hands of professionals and inadequate human service organizations (Mount, Beeman, and Ducharme, 1988).

The abilities required in applying inclusive strategies of persons serving direct community support roles deserve inquiry (Wolfensberger, 1988). The employment duration of community support workers is typically short, which serves to hamper the development of a sound understanding and relationship with the people they support; thus outcomes of community living may be adversely affected (Oberlander, 1990; Braddock and Mitchell, 1992). In a study of attrition among supported employment job coaches, Moore, Godbolt, Schwartz, Moriber, and Salzberg (1991) reported that lack of training and the inability to meet the skill demands associated with supporting the people they worked with were two factors guiding decisions to leave employment.

Two aspects of employee attitudes seem to be important factors related to successful outcomes: job satisfaction and the continuity between the values of the worker and the mission of the organization. Thus staff attitude would be considered as a driving force for community inclusion (Katz and Kahn, 1978; Henry, Keys, and Balcazar, 1996). In a study of community support workers, Henry, Keys, and Balcazar

(1996) found that training in the philosophy of inclusion resulted in more positive worker-inclusion attitudes as well as increased job satisfaction; in addition, the level of worker knowledge of the inclusion philosophy was positively correlated to their self-report of the organization's adherence to inclusion practices. Furthermore, the researchers reported that the knowledge and concurrence with inclusion philosophy has reached the responsible organization implementers; however, it was also noted that the attitude and commitment of direct support staff were not as strong as persons who held leadership positions.

The findings in the Henry, et. al., research effort suggested the need for additional exploration of organizational leadership and vision. A vision statement serves as a beacon describing an organizational future that is comparatively better than the current status; and the leadership is charged with moving the organization forward toward that vision (Bennis and Nanus, 1985). McNulty, Connoly, and Wilson (1996) describe a state initiative that was anchored in the role of leadership to establish self-determination and community inclusion values and to make them clear, understandable, and sufficiently explicit to organizational members, communities, families, and people with disabilities. The researchers stated that the more successful the leadership was in accomplishing these ends,

the greater the likelihood of acceptance and commitment to the values. The researchers also conclude that to forge change, the leadership of human service systems must be value-based, must seek to apply organizational resources to support person-centered planning, and must expect people with disabilities to drive the process (Marrone, Hoff, and Helm, 1996).

Organizational Systems Summary

The ultimate implementation of public policy is carried out by the organizations responsible for arranging or providing services and supports for individuals with developmental disabilities. The contemporary-practice demands of self-determination and community inclusion require values and strategies unlike those applied to traditional service delivery. Self-determination and community inclusion require flexible supports, the access and use of natural community resources and environments, and the relinquishing of decision-making and resource control to individuals with developmental disabilities. Quality demands placed on an organization are consistent with the principles of self-determination (attention to customer preferences) and community inclusion (achieving real-life outcomes). Organizational problems related to moving toward values and strategies consistent with the demands of self-determination

and community inclusion include (a) real or perceived regulatory requirements that diminish staff time needed in providing direct attention to people with disabilities, (b) organizations acting as isolated community actors rather than as partners with the community, and (c) staff turnover and employee attitude. Perhaps the most critical concern involves the variations in organizational members who formally expressed and/or practiced evident commitment to the values of self-determination and community inclusion.

Models of Practice: Housing, Employment, and Education

How and where people live, work, and receive their education are key environments in which relationships are formed with community members and institutions. In the sections that follow, the supported living, supported employment, and inclusive education models of practice are presented as intervention efforts intended on promoting community-inclusive outcomes.

Supported Housing

Over the past twenty years there has been a shift from people with disabilities living in specialized residential programs in the community (group homes) to community living alternatives that are more unique to the individual support needs (Amando, Lakin, and Menke, 1990; Braddock, Hemp,

Bachelder, and Fujiura, 1995). Practices associated with community facility-based specialized residential programs are based on the continuum of care standards requiring that residents obtain approval to enter, remain, or leave the arrangement at the discretion of the professionals; that lack authority for residents to hire or fire para-professionals who work in the home or choose with whom they want to live or room; that provide residents with limited choices even in the areas of daily living and the scheduling and selection of activities; and that limit opportunities for residents to own possessions or acquire meaningful incomes (O'Brien, 1991; Howe, Horner, and Newton, 1998).

Supported living is based on the notion that people desire a place of their own which allows the individual to choose where and with whom he or she will live (O'Brien, 1991; Braddock, Hemp, and Parrish, 1997; Balcazar, MacKay-Murphy, and Keys, 1998). Supporting individuals in making choices is an important consideration of the model. It is based on the core assumptions that individuals with developmental disabilities are capable of making clear, sound, and relevant decisions when offered adequate opportunities for choice (Parsons and Reid, 1990; Vandergriff and Chubon, 1994). Faw, Davis, and Peck (1996) applied an intervention with a small sample of subjects who provided instruction to individuals with mental retardation

to apply in inquiries for residential settings and found the subjects increased their skills in gathering and using relevant information.

Supported living involves assisting individuals with disabilities in securing a home from the natural housing stock in the community and in the resources necessary to support the person in the community (Clees, 1992; Hogan and Carling, 1992; Henry, Keys, Balcazar, and Jopp, 1996). The supported living model acknowledges that living in a home in the natural community provides people with disabilities with a valued sense of place, command over their living environment, and long-term security through ownership and other methods of controlling tenancy (O'Brien, 1991). Supported living treats housing itself as "bricks and mortar" while providing accommodations and supports that assist persons living in their own home through learning about people, their community network, support preferences and needs, and the lifestyle they wish to pursue (Goering, Durbin, Foster, Hons, Babiak, and Lancee, 1992; Racino, Taylor, Walker, and O'Connor, 1993; Sohng, 1996; Howe, Horner, and Newton, 1998; Smull, 1998). Furthermore, the supported living model requires changes in planning supports on an ongoing basis as needed; utilization of in-home and community supports (e.g., para-professional aids, transportation); recognition of the unique desires and needs

of the individual; provision for safeguards in response to reasonable health and safety concerns; and allocation of sufficient resources to the plan (Racino and Taylor, 1993; Howe, Horner, and Newton, 1998).

Typically, supported living arrangements are small in number of housemates as compared to congregate-based specialized residential programs. Several studies have indicated that there is a favorable relationship between smaller numbers of persons within a residence and the outcomes, choice, opportunities, and self-determination of the individuals (Stancliffe, 1997; Conroy, 1996). Howe, Horner, and Newton (1998) conducted a comparative study between residential programs and supported living arrangements, which included an examination of choices regarding housemates, daily decision-making, and planning. The researchers found there was a significant difference between the two subject groups: preferences of individuals residing in supportive living arrangements guided decisions regarding who they lived with, daily routines, and activities and planning. By contrast, researchers who completed a national study on quality of life in specialized residential programs reported that most residents had no friends or family contact and had only minimal engagement in individualized recreational or social opportunities (Hill, Rotegard, and Bruininks, 1984).

Supported Employment

Movement from traditional day programs to supported employment practices contributes to increased community competitive job integration for individuals with disabilities (Drake, Becker, Biesanz, Torrey, McHugo, and Wyzik, 1994). Supported employment is defined as supporting people with disabilities in jobs in natural community settings as they seek to earn a competitive wage as a means of increasing economic self-sufficiency and inclusive experiences (Braddock, Hemp, and Parrish, 1997; Kregel, 1997). Supported work contains four essential components: employment development and placement, on-site training and advocacy, continued assessment activity, and ongoing follow-up and retention efforts (Poole, 1987). Supported work models include individual placements, fixed enclaves, and mobile crews (Rusch and Hughes, 1989). Individual placement is the preferred model of practice.

There is a good fit between the supported employment goal of increased inclusion and choices through the involvement of family members and significant others and the person-centered planning efforts used to determine the individual's vocational preferences and necessary supports (West and Parent, 1992; O'Brien and Lovett, 1992; "Person Centered Planning and Community Action Approaches for

Transition to Employment: Concept Paper and Proposals for Possible Pilot Projects," 1995; Rimmerman, Botuck, Levy and Royce, 1997). Supported employment requires that rehabilitation organizations be centered on understanding the desires of the consumer in order to ensure continuity between the ultimate job placement and the individual as well as to further the efforts of career planning (Revell, Wehman, and Arnold, 1984; Szymanski and Hanley-Maxwell, 1996).

It has been argued that person-centered planning provides an environment for exploring employment as a career rather than simply as a job. Employment then becomes not only a means of income but also a consideration in the improvement of an individual's quality of life ("Shifting Patterns," 1992; Brokke, Revell, and Green, 1998). The use of a natural community focus in the planning process requires emphasis on an individual's preferences and career desires as related to the types of jobs and work environments rather than on her/his deficits and traditional work evaluations based on a single dimension (Rogan, 1996). Further encompassing the community, Stevens, Curl, and Rule (1993) described a program that applied "intersector cooperation" in an effort to inform the community that people with disabilities are community participants, to define the roles of community members in providing

assistance as employers, coworkers, etc., and to provide supports for individual's efforts to engage in recreation, work, and community volunteering.

The work environment provides an optimal arena for human service systems to implement strategies for engaging natural supports (Mank, Cioffi, and Yovanoff, 1997). As part of the process of job development, pursuing strategies for identifying natural supports in the workplace moves from a sole focus on the needs of the individual to a broadened perspective of resources and supports available in the work environment (Fabian, Edelman, and Leddy, 1993; Trach and Mayhall, 1997). Natural supports in an employment situation are intended to build upon the organizational culture of what typically occurs in the work place, within both the formal and informal structures, in an effort to improve job retention; to promote community and workplace socialization and inclusion; to increase consumer satisfaction and individual quality of life; and to improve resource efficiency through the reduction of paid supports redundant to what is available in the work place (Butterworth, Hagner, and Kiernan, 1996; Test and Wood, 1996; Rogan, 1996; Brokke, Revell, and Green, 1998).

Consistent with this conceptual analysis, a study of social interactions across various supported employment models found some models more conducive than others to

social processes in work settings. The analysis supported the role of characteristics of individual employment settings, such as sharing a common work and lunch area, as potential determinants of increased social interactions (Storey and Horner, 1991).

Just as it is in the case of each individual with a disability, there is no template to apply to every employment situation; thus each work place and the relationship with the person are treated as unique in developing natural support strategies (Rogan, 1996). There is some dispute in the field regarding the relationship between traditional supported employment models of practice and natural support strategies. One school of thought assumes that natural supports would simply occur following the intensive phase of job training and support provided by a job coach (Test and Wood, 1996). Another axiom proposes that natural support strategies could be used in lieu of the Job Coach model, with one study finding that there was an increase in reciprocal interactions between individuals with disabilities and their coworkers when using a mentor group design (Lee, Storey, and Anderson, 1997).

In general, natural support strategies in the employment environment engage the involvement of supervisors and employees (Shafer, Tait, Keen, and Jesiolowski, 1989; Likins, Salzberg, Stowitschek, Lignugaris-Kraft, and Curl,

1989; Mank, Cioffi, and Yovanoff, 1997). However, there are workplace-related natural support strategies that potentially maintain a role for human service system's assistance. For example, employees may be provided training to be better informed as to how to provide support to individuals with disabilities and as to how the rehabilitation system could identify natural resources available to all workers and of particular benefit to workers with disabilities (Nisbet and Hagner, 1988; Butterworth, Whitney-Thomas, and Shaw, 1997).

The supported employment model has served to achieve its major goals of providing people with disabilities with wages substantially greater than they received in segregated day programs and of offering opportunities for integrative socialization (Coneley, Rusch, McCaughrin, and Tines, 1989; Kregel, Wehman, and Banks, 1989; McDonnell, Nofs, Hardman, and Chambless, 1989). Mank, Cioffi, and Yovanoff (1998) conducted a study of coworkers who had been trained in work-place diversity and disability awareness and found that individuals with disabilities had increased economic compensation and greater levels of typical participation and social interactions, both within and outside of the work-place, as compared to a group of their peers whose coworkers were not provided the training. Houser and Chace (1993) completed a study of employment satisfaction of individuals

with disabilities working in an industrial project and found that the subjects overall were highly satisfied with their jobs; however, pay and opportunities for advancement were two areas where satisfaction was less evident. Tice (1994) conducted an experimental study in examining community member attitudes toward people with disabilities working in the community and found that subjects in contact with the supported employment workers post-job placement were significantly more likely to work with these individuals and were more favorable to integrated work efforts.

There have been a number of published studies regarding the community business perception of supported employment. In a study comparing employer and rehabilitation professionals' views regarding supported employment, findings showed that the rehabilitation professionals perceived business as participating in these efforts out of altruism while the employer respondents reported the reason as a sound business practice (Fabian, Luecking, and Tilson, 1995). This study indicates that perhaps some segments of the community may be more inclusive than human-service professionals. Similar as to what might be identified as a key factor in hiring employees with no disabilities, in a survey of employer opinions regarding what skills they thought were most important in hiring individuals with disabilities, subjects reported personal, interpersonal and

attitudinal behaviors as most critical (Burton, Chavez, and Kokaska, 1987).

Several studies have shown that people with developmental disabilities demonstrate work and social competencies in the workplace. Self-management techniques (the training of individuals with disabilities to manage their social and work behaviors and to problem solve) have served to improve work performance (Hughes and Rusch, 1989; Park and Gaylord-Ross, 1989; Shafer, 1987; Christian and Poling, 1997). Research by Adams-Shollenberger and Mitchell (1996) confirmed the findings of previous studies that workers with mental retardation are equal to or exceed their non-disabled peers in the areas of turnover and absenteeism. Levy, Jessop, Rimmerrman, and Francis (1993) carried out a study of employer attitudes and reported that the workers with disabilities were described as dependable and performed and interacted well, particularly when appropriate supports were provided. Belcher (1995) examined, for a one-year period, the behaviors of two men with severely aggressive behaviors while they were in a sheltered workshop and then employed in the community; he found a 93% reduction per month in aggressive behaviors exhibited in the community as compared to behaviors while in the sheltered setting. In another study involving eleven individuals with disabilities and incompatible work behaviors, the subjects were moved

from a facility-based day program into an application of the supported employment model, resulting in a decrease of adverse behaviors in their work setting (Zumberg, 1990).

In a research effort examining the application of a consumer choice model for seeking employment, it was found there was an increase in subjects with developmental disabilities securing paid employment as compared to those who did not use the choice model (Thompson, Carroll, Lobb, and Melesky, 1994). Choices within a work setting may also affect work efforts. In a small sample study of task choice and work performance, researchers reported that choice may serve to improve performance of individuals with developmental disabilities (Bambara, Ager, and Koger, 1994).

Supported employment is ultimately measured by the change in an individual's earned income. One research effort focused on comparing income earnings between people in supported employment and facility-based segregated workshops/work activity programs, as well as changes in the level of on-site support needs of the individuals in supported employment arrangements (Ferguson, 1993). The study found that persons employed in supported employment arrangements earned more than twice as much as their facility-based peers and that, over time, these individuals required less on-site support. In a secondary data analysis, researchers reported that socio-demographic characteristics

(e.g., gender, age, race/ethnicity, economic status) were more related to securing employment than either the severity of the individual disability or individual functioning level (Rimmerman, Botuck, Levy, and Royce, 1996).

Organizational experience and competencies as well as staff and management attitude need to be considered in changing from facility-based day programs to supported employment systems (Parent, Hill, and Wehman, 1989; Rogan and Murphy, 1991; Mullins, Roessler, Schriner, Brown, and Bellini, 1997). Characteristics of a segregated workshop can be changed to include more technologies and marketable products, while the integration of workers who are not disabled with workers who have disabilities can be the mechanism for creating an integrated employment setting (Rosen, Bussone, Dakunchak, and Cramp, 1993). To be effective in these efforts toward change, rehabilitation organizations, in pursuing competitive employment opportunities, need to develop partnerships with the business community, school systems, and persons with disabilities (Rochlin, DeCaro, and Clarcq, 1985).

Inclusive Education

Inclusive education is based on the legal premise that all youth with disabilities have the right to be provided a Free and Appropriate Public Education (FAPE) in the Least

Restrictive Environment (LRE) (DeMitchell and Kerns, 1997). Traditionally, youth with disabilities were placed into special education programs provided in a segregated facility with the students needing to "earn their way" into the regular educational system (McNulty, Connolly, and Wilson, 1996). In contemporary practice, inclusive educational efforts are directed at supporting youth with disabilities within regular educational institutions in their communities and neighborhoods (Guralnick and Groom, 1988; McNulty, Connolly, and Wilson, 1996; Pryor, Kent, McGunn, and LeRoy, 1996).

Practitioners and researchers have noted that simply integrating students with disabilities in classrooms with other students does not constitute inclusion. Without an adequate support network in both depth and breadth and the related enhancement of her/his quality of life, placing a student with a disability in a regular educational environment does not provide a guarantee that she/he will develop and maintain community and social connections (Abery and Simunds, 1997). Inclusion in education includes collaborative work efforts between special education and general education teachers using person-centered planning. This approach maintains the youth and her/his family at the center of the process, and it considers necessary in-school supports and accommodations as well as resources available

in the natural community as methods of contributing to the individual's education and citizen development (Vanderccok, York, and Forest, 1989; York-Barr, 1996).

In an examination of inclusion efforts by schools, McNulty, Connolly, and Wilson (1996) conducted a comparative analysis among states and within one particular state. They found considerable variation in the number of children with special education diagnosis among the states, the percentage of children in regular education as opposed to special education, and the percentage of children in regular education as opposed to special education between two school systems. These findings suggest problems with diagnostic applications, and they indicate that access to regular education may be a systems problem rather than a function of disability. These variations are further reinforced in a survey of school administrators, where researchers found a virtual split between proponents and non-proponents of full inclusion for students (Fullwood, Pankake, and Fournet, 1996).

Attitudes, values, knowledge, and behaviors of educators, peers, and individuals with disabilities constitute the interpersonal environment of the classroom. For example, teachers are confronted with children with disabilities who may be exhibiting internalized (shyness and avoidance) or externalized (aggressiveness and acting out)

behavior in reaction to peer rejection and related anxiety and resulting dissatisfaction with these relationships (Taylor, Asher, and Williams, 1987). In a study of paraprofessionals working with adolescents with disabilities in a special education, physical education program, researchers found inservice training and feelings regarding inclusion to be correlated in a manner suggesting the need for inclusive education learning experiences for faculty (O'Connor and French, 1998). Sinderides and Chandler (1996) conducted a research effort comparing elementary teachers in music and physical education, and found music teachers were less favorable to inclusion for students with behavioral and emotional concerns while physical education teachers were less favorable to inclusion for students with physical disabilities. This suggests that the nature of the environments and the manner in which the two groups of teachers provide education influenced their perceptions of students who would benefit from inclusive opportunities (Sinderides and Chandler, 1996).

Rothlisberg, Hill and D'Amato (1994) conducted an experimental study of social acceptance of children with mental retardation by their peers and found the inclusion of a disability label had an adverse affect, indicating the label may inhibit acceptance by peers. In a research effort on mainstreaming, findings indicated no improvement in

social status (social acceptance/rejection) for students with mental retardation who had been mainstreamed for an average of 4 years as compared to a group averaging 1.7 years (Brewer and Smith, 1989). In a single-subject study involving three subjects and competency and social engagement through the use of a computer game, Breen and Harring (1991) found that the increased level of skills of children with disabilities in structured integrative activities was related to increased peer-related social initiations as well as game satisfaction.

Ziegler, Taylor and Scott (1996) conducted an experimental study regarding conflict resolution and perceptions of school behavior and self-concept with students assigned to an inclusive school English class, a conflict resolution group, and a general education English class. The researchers found that on measures of self-concept and school behavior, subjects in the inclusive group scored significantly higher in comparison to subjects in the general education group and, although not statistically-significant, they also scored higher in comparison to the conflict resolution group (Ziegler, Taylor and Scott, 1996). This suggests that intended inclusive opportunities may lead to a better sense of self as exhibited through general and interpersonal behaviors. In a single-subject design study of three children with disabilities in choice making and

related problematic behaviors, the investigators found a positive relationship between allowing choices in the selection of tasks and reinforcers and the reduction of serious behaviors (Dyer, Dunlap, and Winterling, 1990).

Even if greater numbers of children with disabilities are included in regular education classrooms, without sufficient supports, school mainstreaming efforts will not achieve inclusion outcomes (Horrocks, 1993). There are a number of strategies based on educational systems being applied and evaluated in an effort to best achieve social and school inclusion (Meyer and Biklen, 1992; "Person Centered Planning and Community Action Approaches for Transition to Employment: Concept Paper and Proposals for Possible Pilot Projects," 1995; Hoffman and Field, 1995; McNulty, Connolly, and Wilson, 1996; Hardin and McNelis, 1996; Villa, Thousand, and Chapple, 1996; Abery and Simunds, 1997). Various strategies include:

1. Collaborative efforts between state and local school systems, families, and advocacy groups.

2. Co-learner approach to a teacher-student dyad for developing an understanding of self-determination.

3. The pairing of youths with disabilities and youths that do not have disabilities acting as co-mentors.

4. Educator and administrator teams to provide inclusion-related consultation to school personnel.

5. Education programs providing continued development of faculty skills in inclusion.

6. The placement of both general and special education students into a combined inclusive elementary education program.

7. Community life facilitators matched with a person with a disability.

Central to all of these strategies is the concept of building community relationships.

Models of Practice Summary

The supported living, supported employment, and inclusive education models of practice share two key commonalities: Each is concerned with supporting people in natural community environments and advancing the individual's development of responsibilities and relationships in the community. All three community-inclusive models also seem conducive to self-determination principles and person-centered practices. Individuals with developmental disabilities are provided choices regarding where and how they want to live and what types of employment they desire with accommodations in school and supports being unique and flexible. These models are a departure from the practices of traditional residential, day, and special education programs.

Summary of Context

These systems, families, communities, and organizations may contribute to or detract from self-determination practices and community-inclusive outcomes. Furthermore, these systems appear independent, interdependent, and dynamic in nature; they are influenced from within and by other contextual forces.

Family needs change throughout the life cycle. Self-determination principles and person-centered planning are intended to be conducive to meeting the demands of changing needs. Organizations responsible for serving and supporting people with developmental disabilities are challenged to respond with flexible supports and practices to meet the needs of consumers and their families. Community inclusion requires that families, organizations, and the community acknowledge that people with disabilities are competent to form meaningful relationships with ordinary people and natural places in the community. The development of these relationships are intended to contribute to the development of a natural support network for the individual with a developmental disability with specialized supports provided by the responsible organizations serving to augment what is not accessible or available in the natural community. The identification and securing of natural supports in the

community require that organizations become active community entities. Models of practice such as supported living, supported employment, and inclusive education are intended to promote access and utilization of natural community environments which ultimately lead to community-inclusive outcomes.

SUMMARY AND IMPLICATIONS FOR RESEARCH

As presented in the review of literature, the concept of self-determination requires a set of values and practices that presume individuals with disabilities are able to make life decisions, control resources, and develop relationships with ordinary people and natural places in the community. Furthermore, the literature indicates that these philosophical beliefs and corresponding practices require a commitment by families, supporting organizations, and ordinary community members, and natural institutions. Self-determination is pursued through person-centered practices focusing on supports, accommodations, and relationships in the natural community. Community-inclusive opportunities and experiences, with ordinary people and places in the community, are proposed as the outcome of self-determination practices. It is argued that this process of developing relationships provides people with opportunities for the basic right of full citizenship. These relationships are

reciprocal in nature: all parties are involved in give-and-take, cost-and-benefit arrangements.

Based upon this review it appears that there are three critical components of self-determination: (a) the concept of freedom to access and control a defined set of financial resources as applied in the process of purchasing supports and means of accommodation, (b) the concept of individualized support necessary to pursue life desires in the community, and (c) the development of valued supportive and reciprocal relationships with those significant to the individual as well as with other people and social institutions in the natural community.

Potential Areas for Research Inquiry

Central to the concept of self-determination is consumer choice. However, choice itself is potentially subject to both opportunities and barriers as influenced by framework and contextual considerations. An area deserving exploration involves the dynamics of internal and external relationships as influencing choice. Internal is defined as the individuals who are part of the individual's person-centered planning efforts while external describes the community context. Internal dynamics include the manner in which individuals, aligned as supporters of the person with the disability, effect person-centered decision-making. This

includes the level of focus and attention in the process afforded to the individual as well as the level of power relinquished by others involved.

As related to community capacity, it is plausible to propose that the actors comprising the internal set of relationships as well as the individual with the disability are influenced by the external forces. For example, community capacity includes factors such as accessible housing and employment as well as social attitudes toward people with disabilities. These external considerations were described in the framework and contextual perspectives offered in the review of literature.

Each of these external factors are inherently related to the concepts of self-determination and community inclusion. Economic considerations include factors such as poverty and financial resources primarily earmarked through policy to support systems as opposed to individuals. These create a potential conflict in the allowance of an individual's control over funds. Social stigma, be it known or not known to individuals, could serve to limit opportunities for the person with the disability in making life choices. Ethical considerations, from the perspective of individual professionals as well as responsible organizations, could also hamper consumer-driven decision-making processes and life pursuits. Also of interest would

be an examination of any potential mitigating effect of these external forces resulting from the ideals legally established through public policies such as the Americans with Disabilities Act and the Rehabilitation Act.

The study of these forces could consider the micro- and macro-fields. There is a potential interplay between the micro- and macro-levels. Person-centered planning does not occur within a vacuum with the only world being the individuals involved in the planning efforts. Additionally, the efforts of person-centered planning, taken at a collective level, could conceivably shape the external environment. For example, the greater the number of individuals with disabilities, along with ordinary community members in a community involved in person-centered planning and self-determination practices, could result in greater demand for and access to community-inclusive opportunities. This would in turn create increased community capacity.

A number of empirical studies cited in the review of literature support the need to examine more closely the relationship between individual and environmental factors serving as the arena and conduit for self-determination practices and community-inclusive outcomes. There is a more fundamental concern that is deserving of exploration: an examination of the ideology of self-determination and community inclusion as embedded in public policy and as

related to the process of conceptualizing these values and operationalizing corresponding practices. Thus, this would involve a study of the implementation of relevant public policy.

Several studies spoke to the importance of an understanding of and commitment to a particular set of values for achieving practices and outcomes consistent with said values. These were reported as related to individuals as well as groups. For example, differences between the leadership and direct support staff within organizations indicate that the values and practices are not in concert. While there may be support at the leadership level, the implementation of new ideologies resulting from public policy may not be completely integrated into the beliefs and practices of the organization resulting in organizational shortcomings in efforts to achieve policy intentions accurately and completely.

The relationship between concepts of dependency, independence, and interdependence and the contextual considerations presented in the review of literature deserve inquiry. The three eras of deinstitutionalization and community inclusion are reflective of these three concepts. The process began with a dependency orientation: persons totally dependent on care and treatment within institutional arrangements. The second phase was independence focused:

persons residing in multiple community-based institutions with increased freedoms granted as they demonstrated functional improvements described as independence. The contemporary phase is interdependent in nature; people are included in the community in reciprocal relationships with other people and social institutions while receiving specialized supports and accommodations that are not available in the natural community.

The key question revolves around the manner in which the experiences and perceptions of the persons involved in supporting individuals with disabilities influence the accurate and consistent application of self-determination practices and understanding of community inclusion. How do the critical actors delineate the concepts of interdependence, independence, and dependence as related to the model specifications of self-determination and community inclusion? How do these understandings and perspectives affect the values necessary to pursue self-determination practices and community-inclusive outcomes?

As was indicated in the literature, families of individuals with developmental disabilities are a key source of influence. Families with members who are disabled are faced with a host of stress-related issues. These issues occur throughout the life-span, beginning with concerns upon receiving the news that a child has a diagnosed disability

and continuing through the uncertainty of caregiving for an adult child after the parents' death. In addition to the stress created within the family unit and their natural support network, families are faced with needing to deal with systems designed to provide supports and services to them and their children. As families are key contributors in the planning and delivery of supports and services, the issue of trust and faith in the systems involved becomes an area of interest for study. Particularly in light of past experiences with these systems and movement into new practices, families are faced with the continuing process of systems indicating that "this new way is the correct way to support your son or daughter, not the way we told you before."

Professionals are faced with several potential belief-system and practice dilemmas. Central to these issues are power, the perceptions of the people whom they serve, and ethical considerations. Inquiry is warranted to examine changes in the power relationship between people with disabilities and their families and professionals providing services. Furthermore, the examination of a relationship between perceptions of a need for power and control by the professional as related to questions of perceived and real client competency would seem to be a viable research path. In addition, the role of ethics would be of interest to

examine, particularly as related to the identification of legitimate and illegitimate concerns. Specifically, the question regarding the reframing of professional ethics is a deserving area of inquiry. Individuals are faced with dual roles; as professionals in clinical matters and as friends when identified by individuals with disabilities as participants in person-centered planning efforts. This duality, coupled with the clouded boundary between the roles, requires a close exploration of the variability of ethical postures.

Professionals involved in providing supports and services to people with disabilities typically are employed by organizations. Thus, the relationship between the organizational leadership and subordinate personnel and contract vendors requires consideration in developing a full understanding of the values and practices of the professionals. Organizations are challenged in establishing a vision and values consistent with the policy initiatives regarding self-determination and community inclusion. There are several aspects of these responsibilities that warrant study.

From a horizontal perspective, a question is raised regarding the continuity between an organization's stated values and its practices. Additionally, from a vertical perspective, a question is raised regarding the continuity

between the organizational leadership and the front line managers and implementers. From an internal perspective (within the organization), interest is in any variation of values and practices between the formal and informal organization. From an external perspective (between the organization and forces outside of the organization), interest is focused on the relationship between the values and practices with consumer, family, and community stakeholders. In this last regard, this would include examining the boundaries evident between individuals and groups considered as internal to the organization and those considered to be external. This is of particular interest given that self-determination practices and community-inclusive outcomes suggest that supporting organizations would need to be much more embracing of people and groups considered to be external to the organization.

As was evidenced in the review of literature, the subject matter itself is at a stage of knowledge infancy. Empirical-based studies were limited in some areas and reflected a tactical approach. For example, there was a good number of research efforts that have been conducted regarding supported employment, while there was virtually no scientific examination of person-centered planning. This might best be explained with regard to the evolutionary development that has occurred. The concept of supported

employment emerged prior to the concept of person-centered planning. This example also provides the foundations for an emerging strategic research agenda. As components such as person-centered planning, self-determination, and community-inclusive opportunities and outcomes become operationalized, the manner in which supported employment is examined becomes more rich. Thus, the latter studies in this area included the concept of person-centered planning as applied to career planning and introduced the concept of accessing natural supports in the workplace.

The literature suggests that the core of a strategic research agenda related to self-determination and community inclusion could be developed from the notion of relevant values and practices within the contextual environment. Such an exploration would examine the relationship between critical actors' values of self-determination and community inclusion and the actual practice of these concepts, as manifest in models of planning and support.

Central to this strategic core are organizations. Organizations serve as:

1. Entities with leadership responsible for establishing a set of organizational expectations necessary for adequately and accurately pursuing public policy relative to self-determination practices and community-inclusive outcomes.

2. Bridges among contextual forces--people with disabilities, families, and communities.

3. Agents responsible for applying support-oriented models of practice that include individualized provisions of supports and accommodations where they are not available or can't be accomplished using natural resources.

4. Systems influenced by external tensions (e.g., social) and internal dilemmas (e.g., ethical).

5. Agents of policy implementation responsible for the allocation and management of human, technical, and financial resources.

As the key agents of public policy implementation relevant to these concepts, organizations could serve as the focus of this proposed area of study. Research inquiry could be developed particularly around the manner in which leadership defines, establishes, and communicates the values and practices that are most conducive to the policies being implemented. This includes the manner in which consumers, families, and community members are involved in the organizational planning process and how the membership within the organization is involved with and oriented to change. Furthermore, study in this area could include a close examination of the relative degree of fit between the organization's vision, mission, and values and its actual application of self-determination practices and as related

to the achievement of community-inclusive outcomes through the intermediary actions of staff.

Conclusion

As evident in this section, the research potential in the area of self-determination and community inclusion offers vast opportunities. The use of organizations as a strategic core is proposed as a key research area. Although focus of this nature is critical in order to adequately maintain the scope of study, the inclusion of the framework and contextual considerations presented in this or any proposed research effort would provide a broad perspective for exploration into this underdeveloped area.

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CHAPTER 2: SPECIFIC AIMS

This research effort focuses on organizations as agents of policy implementation. The particular policies investigated were related to the concepts of self-determination and community inclusion.

This chapter begins with a brief presentation of the evolution of the community movement for people with developmental disabilities and a summary of the concepts of self-determination and community inclusion as drawn from the learning provided in the review of literature. Next, the scope of the inquiry is presented. This is organized to include the key research questions and a conceptual description of the relevant variables.

RESEARCH OVERVIEW

As presented in the literature, public policy has reflected an evolving commitment to supporting the deinstitutionalization of people with developmental disabilities. Initially, most efforts focused on the most concrete and practical aspects of deinstitutionalization. Thus, policy implementation involved the movement of people with developmental disabilities from large, segregated facility-based institutional arrangements into the community. This could be defined as the first generation of

the deinstitutionalization efforts: the era of community-based case care.

The second generation of deinstitutionalization involved policies that supported the financing of defined and sophisticated community-based service delivery models of practice: the creation, refinement, and advancement of a system of specialized and primarily segregated community-based institutions. This era found the development of specialized, residential programs, day treatment/programs, and client and care service management. The community-based institutional system involved a web of specialized managed services and resources segregated from the community.

The policies of the third generation of deinstitutionalization were intended to reduce entry into large facility-based institutions as well as smaller facility and systems-based community institutional arrangements. Efforts focused on people with developmental disabilities who had never experienced facility- or community-based institutionalization. These individuals were typically minor children or young adults who lived with their families. This era found the advent of care and service coordination practice as people with developmental disabilities and their families were linked to both natural and institutional community services and resources.

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deinstitutionalization: the era of full community inclusion. The diminished census in large facility-based institutions, the questionable effectiveness and efficiency of community-based institutional systems, and the aging of families have all created a need to move away from the notion and practice of institutional approaches for people with developmental disabilities. In addition, the evolution of the disability rights movement has contributed to increased levels of freedom for people with disabilities. Thus, from a policy perspective, this might be defined as the transition from the disabilities rights policy era to the full citizenship policy era.

The contemporary era has introduced the following concepts:

1. Focus on the abilities of people rather than disabilities.

2. Support coordination as opposed to case management or client service management or service coordination.

3. Support and accommodation of people as opposed to the concepts of specialty services and clinical care and treatment.

4. The introduction of support-based models of practice that utilize highly integrated natural community resources and relationships (e.g., support to live in regular community housing, support for people with disabilities to

develop friendships with other community members) as opposed to service delivery programs contained within a web of primarily segregated specialized community institutional arrangements.

5. The introduction of processes that place the individual with the developmental disability in command of support and service decision-making as opposed to planning and decision-making based on clinical determinations that do not involve the individual with the disability in a valued or purposeful role.

6. The introduction of a process that places the individual with the developmental disability in command of resource decision-making resulting in the implications of finance shifts from fixed-cost institutional arrangements to flexible community supports.

Key Concepts

The change of philosophy and values is at the core of the continued community movement. Clinical practices had a developmental focus with the developmental model supporting practices of "cure, care, and continuum." People with developmental disabilities only advanced from institutional arrangements through a series of steps as they demonstrated mastery of functions determined necessary for the right of ultimate participation in an ordinary community. Thus, if an

individual was unable to achieve mastery in a particular "key" function, passage to the ordinary community was virtually unobtainable.

Contemporary policies, processes, and practices reflect concepts that are anchored in a very different values framework. For the purpose of this study, two concepts were explored: self-determination and community inclusion.

Self-Determination

In simple summary, self-determination is defined as a dynamic process and practice whereby individuals with a developmental disability are supported in opportunities to define life ambitions and to determine the types of supports, accommodations, and services they desire in pursuit of said life ambitions. These opportunities place the individuals with developmental disabilities in command of the decision-making process and grant them control of resources.

The concept of self-determination has evolved over time. The disability rights movement sparked the initiation of the fundamental assertion that people with disabilities are valued individuals: people with abilities and talents. The emergence of disability rights policy, including the role of the courts in advancing policy, further institutionalized the assertion of citizen rights for people

with disabilities. Practice models intended to be consistent with policy began to emerge as concepts of case management/coordination models included advocacy as the core function.

Clinical practices were typically not conducive to providing processes that most fully allowed people to be at the center of decision-making. Therefore, new process models were developed. These included considerations for examining the decision-making environment to better assure that:

1. The arrangement of resources were conducive to an environment that would not restrict deliberations in decision-making regarding the types and amounts of valued real-life opportunities for people with developmental disabilities.

2. The arrangement of the decision-making hierarchical-order places the individual client in the role of ultimate command and control of life planning and decision-making.

The concept of self-determination is not without boundaries. However, issues related to parameters create the types of difficulties that are to be resolved through adherence to the self-determination values framework. Boundary considerations include:

1. Health and safety concerns of both the individual and other members of the community.

2. Perceived and/or real liability concerns of

professional practitioners and support and service systems.

3. Potential legal implications of particular decisions.

4. Personal values and ethical challenges posed by particular decisions.

5. Perceived and/or real resource limitations.

Community Inclusion

Community inclusion is described as experiences and life outcomes of people with developmental disabilities within the ordinary community using natural community resources (e.g., regular places of employment, regular community housing) and through the development of natural relationships (e.g., friendships, work peers). Support practices and disability-related accommodations (e.g., environmental modifications, technological adaptations) are applied in an effort to promote an individual's life in the ordinary community.

As presented through the history of deinstitutionalization offered in the literature review, the concept of community inclusion has developed over time. Some of these literature resources focus on the movement from large, segregated, facility-based institutions to the community. However, as described in other relevant literature, the aspect of community is much more broad and

complex.

At the foundation of the notion of community inclusion, the definition of community would include the following components:

1. A system of fully-integrated natural arrangements accessible to all members.

2. An interrelated set of valued social institutions and practices.

3. A paradigm operating within a prescribed set of social and cultural norms, respecting the inherent right of the individual as primary and as reconciled with the compelling social need of reasonably-assumed justice-based individual and collective protections from potential harm.

4. An environment where an individual with a develloPmental disability is continuously afforded opportunities and experiences for the development of reciprocal relationships with natural places and ordinary people.

In addition, the community requires the active participation of all of its members and provides a level of support and accommodation to its members. For example, with regards to the latter, a community may offer transportation services to accommodate members who would be best served by means of mass transit or for members who can only afford public transportation.

In contrast, the traditional notion of community for people with developmental disabilities is rooted in a very different definition. The community would be defined as a self-contained, primarily segregated system of continuum-based, comprehensive, specialized services and arrangements accessible only to people with developmental disabilities (with access determined by professionals who worked with these individuals). These community-based institutions would operate within a prescribed set of clinical protocols and programmatic practices respecting the narrowly-defined rights of the individual while protecting both the individual and/or other community members from perceived or real potential harm.

In addition, people with developmental disabilities could only participate within this fabricated community to the level they demonstrated mastery of the skills determined necessary to gain increased independence and in which they could "fit" into arrangements that provided minimally-required support and accommodation. With regards to the latter, for example, an individual with a physical handicap may be required to live, and indefinitely remain living, in a specific home deemed accessible.

In part, the notion of community has simply involved the process of moving people from large, segregated, facility-based institutional arrangements into a

"fabricated" community: a web of segregated community-based institutional arrangements. Furthermore, with regards to the physical plants contained within this community, it is apparent that the concept of "bricks and mortar" has not been delineated from the concepts of providing services, supports, accommodation, treatment, or care.

It is logical and plausible to propose that this community is overly redundant to the offerings in the ordinary community. For example, housing is available in the ordinary community while the institutional community offers specialized residential programs. In addition, the practices within this community simply seem to mirror the practices that occurred in the large facility-based arrangements. The institutional community and related practices may indeed send an adverse message to other members of the ordinary community with regard to people with disabilities. Thus, there are potential practice, financial, human, and social costs resulting from this limited notion of community.

Community inclusion requires that people with developmental disabilities have access to opportunities to participate fully in the ordinary community using natural community resources and through the development of a natural support network. At the same time, the real notion of the individual's disability is addressed. Across the philosophies of science and as translated into practice,

there has been movement from the period of dependency ("do all") to independence ("do nothing") to finally acknowledging that people are inherently interdependent beings. Therefore, the notion of providing individuals with support and accommodations to meet the individual's unique, real disability-related needs is applied. Support and accommodation efforts are intended to increase the likelihood that the individual's desires for valued community participation and improved quality of life are best achieved and continually improved.

The concepts of support and accommodation are the elements of community inclusion that provide an avenue of access to the community for people with developmental disabilities. However, there is also a need for the adequacy of community resources and community values that actively support the notion of the inclusion of people with disabilities in the ordinary community. This aspect requires community capacity-building.

Community capacity-building does not occur as a result of the support and service system assuming sole responsibility for the finance and pursuit of community resource development. Community capacity-building requires an active partnership between the support and service system and other natural community members and institutions. This partnership is intended to develop a community that has

resource sufficiency and a desire to include people with disabilities in the sharing of valued natural resources and as full participants in the community. As an example, rather than the support and service system financing the construction and operations of a specialized residential program, community partners may work to develop and/or secure affordable, desirable, and safe housing while the support and service system finances the in-home supports.

Summary of Concepts

Although self-determination and community inclusion are unique and individual concepts, they are inherently related. As individuals are engaged in self-determination, processes and practices that focus on real life desires, life opportunities and experiences in the ordinary community become manifest. Thus, support models of practice and efforts for accommodating people with disabilities in natural community environments using natural community resources would become necessary.

SCOPE OF INQUIRY

Organizations involved in the implementation of self-determination policies and practices for people with developmental disabilities are influenced by the contextual and framework forces described in the review of literature.

These forces are both internal and external to the organization. Internal forces include the organizational staff as individuals with diverse characteristics, beliefs, knowledge, and experiences as well as the manner in which these factors shape the organizational environment. External forces that serve to influence the nature of the organization include formal policy as well as social and constituent expectations. Furthermore, the relationships and interactions between internal and external forces, including consistent as well as conflicting influences, provide the dynamic energy for continuous organizational evolution.

The focus of this research effort was on the internal aspect of organizations responsible for providing or arranging supports and services for people with developmental disabilities. The concepts central to the specific aims are as follows:

1. Support for self-determination (as a set of practices).

2. Community inclusion (as a set of outcomes).

It should also be noted that the concept of person-centered planning is included as a component of self-determination practices.

Self-determination and community inclusion are first established in theoretical terms as philosophies and as they have been conceptualized in public policy. These concepts

each form a fundamental values base from which responsible organizations develop methods of implementation. The process of implementation is defined in two sequential and related components. First, the agencies, initially and on an ongoing basis, need to assure that members of the organization develop concept relevant values and knowledge. Second, the organization is responsible for implementing, monitoring, evaluating, and continually improving practices conducive to self-determination, toward the goal of achieving community-inclusive outcomes. Competencies, as related to individual organizational members and the organization as a whole, are established within the scope of values, knowledge, and practice.

Thus, three factors are associated with each of the concepts, and the research interest, as follows:

1. Values: Belief system regarding the concepts being studied (interest in degree of accuracy).

2. Knowledge: Understanding of elements, constructs, and applications of the concepts being studied (interest in degree of consistency with the values and level of accuracy in understanding).

3. Practice: Self-described activities that are intended to reflect the operalization of the concepts being studied (interest in the degree of consistency with the values, level of accuracy in understanding, and evidence of

the concepts being applied).

Research Questions

The three research questions are as follows:

1. Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion?

2. Between the direct and indirect organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concept of self-determination and community inclusion?

3. Between leadership and line organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concepts of self-determination and community inclusion?

The first question inquires as to the formal systems in place that provide evidence that the organization is directed and operating in a manner that supports and promotes each of the two concepts. The second and third questions examine the organization from a vertical (direct and indirect organizational members) and a horizontal (leadership and line organizational members) perspective as related to each of the two concepts.

Organizational Philosophical Framework

Central to the research questions is the philosophical framework of the organization. The organization's philosophical framework consists of the formal and informal normative standards as communicated, as manifest in relationships between human, financial, and technical resources, and as exhibited through practice.

As related to the two concepts examined, the organization's philosophical framework is evident in the values, knowledge, and practices of the organization, as follows:

1. Values: Conceptually stated in the organization's vision, mission, values statements, strategic plan, and policies and as articulated by organizational members.

2. Knowledge: Substantively described in the organization's vision, mission, values statements, strategic plan, policies, procedures, and practice protocols and as articulated by organizational members.

3. Practice: On a micro-basis, observable in the individual (client) manner in which things are done and how close this approximates the concepts. On a macro-basis, observable in the overall manner in which things are done and how close this approximates the concepts.

Professional Characteristics

The characteristics of individuals who define the nature of their professional selves directly influence the characteristics of the organization and deserve consideration as a potential extraneous factor. For example, as described in the review of the literature, there were several empirical-based studies that described differences in perceptions of as well as commitment to self-determination and community inclusion-related values for people with developmental disabilities between leadership and front-line organizational members.

The following professional characteristics were examined as control variables:

1. The current organizational position/capacity held by the individual.

2. The duration of time the individual has served in this current position/capacity.

3. The duration of time the individual has served as a member of the organization.

4. The duration of time the individual has served working with people with developmental disabilities.

5. The duration of time the individual has served in the human services field.

6. The types of positions/capacities in which the person has served during his/her tenure in the field of

developmental disabilities.

7. The types of positions/capacities the person has served in during his/her tenure in the field of human services.

8. The individual's credentials including undergraduate and/or graduate degree(s), relevant certification(s) and/or licensure, and/or other substantial general professional training/education.

9. Relevant technical and/or substantive training in the area of self-determination.

10. Relevant technical and/or substantive training in the area of community inclusion.

Items one through three provide information regarding the individual's current status as well as duration as a member of the organization and movement within the agency. Items four through seven provide evidence of the variations in capacity and tenure of the individual in the field of developmental disabilities as well as in general human services. Items eight through ten provide descriptions of the individual's general professional education as well as specific professional training as related to self-determination and community inclusion.

Personal Characteristics

The personal characteristics of the individuals are also considered as potential extraneous factors, and thus serve as additional control variables. Although the literature revealed limited empirical efforts examining personal characteristics, there was considerable research evidence regarding the perspectives of families with members with developmental disabilities. Thus, general demographics and relationship proximity to people with developmental disabilities were considered within a set of personal characteristics of the subjects.

The following personal characteristics were examined as control variables:

1. Age
2. Gender
3. Race/ethnicity/culture
4. Whether the individual has a disability (and type of said disability)
5. Whether the individual has/had an immediate family member (parent, sibling, spouse/romantic partner, and/or child) with a disability (and type of said disability)

The above items one through three gather general demographic information regarding the individual while items four and five serve to identify the proximity of the individual to disabilities.

CHAPTER 3: METHODS

The purpose of this chapter is to describe the methodology for the research effort. Methodological considerations include subject description as well as the process of recruiting, selecting, and securing the consent of the participants and a comprehensive presentation of data and information collection processes.

As presented in the Specific Aims chapter, this research effort involved the participation of organizations responsible for providing and/or arranging supports and services for people with developmental disabilities. Sources of data and information included both human participants (organizational members as individuals and groups) and organizational artifacts (documents developed and maintained by the organization). Both quantitative and qualitative data and information was collected using surveys, focus groups, and content analysis methods.

PARTICIPANTS

Four (4) organizations served as the ultimate participants of this research effort. The description of participants as well as recruitment, selection, and consent are provided in the following sections.

Description

Three (3) sample groupings were used which are identified and initially described as follows:

1. Organizations (Groups): This is the ultimate sample base. A non-probability based approach was applied in developing a pool of potential organizations.

2. Organization Documents (Artifacts): A non-probability based approach was applied with participating organizations being required to provide specific documents.

3. Organizational Members (As Individuals and as Groups): A non-probability based purposeful sample was applied based on a stratification by employee position within the participating organizations.

Recruitment

A total of four (4) organizations were needed for the selected sample. These organizations are defined as local, legal organizational entities charged through public policy by the state, or contractual arrangement with a local public entity to carry out the policy of the state, as primarily responsible for providing and/or arranging (via contracts and/or provider networks) supports and services for people with developmental disabilities.

These sites needed to be organizations serving in the capacity of a Robert Woods Johnson (RWJ) Self-Determination

pilot site for at least the past two years (beginning no later than October 1, 1997). The organizations involved were all from a single mid-western state.

The Robert Woods Johnson (RWJ) Foundation funded self-determination initiatives in eighteen (18) states. These initiatives were initially funded in 1996 as three (3) year projects intended to promote the implementation of the concept of self-determination for people with developmental disabilities. The concept of self-determination, which was described in detail in the first chapter, involves people with developmental disabilities driving the decision-making process regarding life desires and support needs, and it includes controlling human and financial resources involved in purchasing supports and services (e.g., developing individual support budgets, client control in support staff hiring and firing). Initiatives were awarded to organizations involved in the management and/or delivery of supports and services for people with developmental disabilities. The National Program Office on Self-Determination at the University of New Hampshire, Institute on Disability is involved in the evaluation of the overall initiative and provides technical assistance, consultation, and training. Additionally, each state involved in the initiative employs or contracts with at least one individual to provide oversight, technical assistance, consultation,

and training to the sites.

RWJ national- and state-sponsored technical assistance, consultation, and training support occurs at the onset of each initiative and continues to be made available throughout the life of the project. Training is targeted for leadership and line staff as well as for organizational members involved in the direct delivery of supports and services and those individuals involved in providing administrative support to the agency. The involvement of organizational members from across the organization in the development of self-determination based competencies is vital as the initiative involves the comprehensive commitment, understanding, and participation of the organization.

The focus of these educational efforts include training in the values and practices associated with the model of self-determination (e.g., person-centered planning, development of individual support budgets). Technical assistance and consultation efforts may be individualized (e.g., designed to respond to the unique needs of an organization) or more general (e.g., developing organizational competencies and capacities in developing community-inclusive innovations). All of these supportive efforts are intended to promote self-determination conducive, comprehensive systems change within organizations. That is, it creates an organizational environment where all of its members begin to speak a common

relevant language and make a commitment to self-determination values.

The four (4) organizations that participated in this study were the initial sites in the state in which this research effort was conducted. One additional organization was also a part of the initial initiative and was originally selected and had agreed to participate. However, as a result of a personal family matter that arose with a key stakeholder of the organization, the mechanics of completing the arrangements for participation in a timely manner were not able to be achieved. Four (4) additional organizations are also presently participating in the self-determination initiative in this state, but these organizations have only recently become active and therefore did not meet the two (2) year minimum involvement in self-determination criterion necessary for participation in this research effort.

The purpose of using organizations involved in the RWJ initiative is two-fold. First, one of the critical concepts involved in this study is self-determination and people with developmental disabilities. Thus, these organizations are deliberately involved in the implementation of relevant practices of interest to this research effort. Second, the manner in which self-determination related technical assistance, consultation, and training is provided to the sites allowed organizational members to be exposed to the

roles and responsibilities of an agency engaged in self-determination efforts. The central concept of moving resource-related decision-making from the agency to the client in itself requires a very different way of doing business and of viewing and treating people with disabilities, across and throughout the entire organization. The desire of this research effort was to identify organizations who had a good probability of being exemplars in this regard and these were provided through the RWJ initiative.

During the recruitment stage, organizations were informed of their commitment to the research effort. Commitment is defined in terms of the consent, information, and timeline requirements, including organizational member time and effort. A copy of the recruitment letter and attachment is included as Appendix A.

Recruitment efforts were initiated approximately forty-five (45) days prior to the scheduled time period for site visits and concluded fifteen (15) days prior to said site visit schedule.

Selection: Stage One

The selected organizations were contacted no later than fifteen (15) days prior to the site visits to inform them of their selection, secure their consent, schedule the site

visit, and request specific pre-site visit information. A copy of the letter of selection, which includes the request for pre-site visit information and consent, is included as Appendix B.

A brief description of the organizations involved in this research effort are as follows:

1. Organization A: Public community mental health system directly providing and/or arranging for through contractual arrangements comprehensive supports and services for people with developmental disabilities, people with mental illness and children with severe emotional disturbances as well as community prevention services. The organization serves a single fringe county (a fringe county is defined as a county with at least one city with a population of 3,000 or greater) with a population of just over 100,500 and has an annual operating budget of just over $14 million.

2. Organization B: Nonprofit organization under contract with a single county public community mental health system directly providing and/or arranging through contractual arrangements comprehensive supports and services for people with developmental disabilities. The organization serves a single urban/suburban county with a population of just over two million and has an annual operating budget of just under $114 million.

3. Organization C: Public community mental health system

directly providing and/or arranging for through contractual arrangements comprehensive supports and services for people with developmental disabilities, people with mental illness and children with severe emotional disturbances as well as community prevention services. The organization serves a single fringe county with a population of just over 75,500 and has an annual operating budget of just under $13 million.

4. Organization D: Public community mental health system directly providing and/or arranging for through contractual arrangements comprehensive supports and services for people with developmental disabilities, people with mental illness and children with severe emotional disturbances as well as community prevention services. The organization serves two fringe counties (in this situation, one county may be described as fringe) with a combined population of just over 106,000 and has an annual operating budget of just under $15 million.

Selection: Stage Two

Between twenty (20) and fifteen (15) days prior to the scheduled site visit, the four (4) ultimately selected organizations were contacted and informed of the participants needed. The Chief Executive Officer (CEO) and a Board member (selection at the organization's discretion) were always included as participants.

As described in the Off-Site Data Collection section of this chapter, each organization was divided into quadrants. The following describes the nature of each quadrant and the participant types:

1. Quadrant #1: Consumer support and service related/indirect/management roles. Leadership, administrative, and management staff responsible for the oversight of services and supports and service and support personnel (CEO and Board members included in this quadrant). Three (3) participants were selected. The CEO, a Board member (selection at the organization's discretion) and the person identified as the top administrator for supports and services for people with developmental disabilities.

2. Quadrant #2: Consumer and service related/direct/line roles. Case Management, Support Coordination, Client Service Managers, Clinical staff and community para-professional staff responsible for providing direct consumer supports and services. Five (5) participants were selected. The researcher selected by position while the actual participants were identified by the organization consistent with the position selection parameters developed by the researcher.

3. Quadrant #3: Non-consumer support and service related/indirect/management. Leadership, administrative, and management staff responsible for the operations of the

organization including finance, personnel, and quality functions. Two (2) participants were selected. The person identified as the top finance manager and one (1) additional person. For the second participant, the researcher selected by position while the actual participant was identified by the organization consistent with the position selection parameters developed by the researcher.

4. Quadrant #4: Non-consumer support and service related/indirect/line staff. Finance, personal, quality and other line staff responsible for providing direct support and services in the operation of the organization. Three (3) participants were selected. The researcher selected by position while the actual participants were identified by the organization consistent with the position selection parameters developed by the researcher.

As evident above, the plan called for thirteen (13) members of each organization to participate in this research endeavor for a total of fifty-two (52) participants. However, at the time of the researchers site visit it was discovered that Organization C had one additional consenting participant. The researcher decided that this individual could be included. This additional participant created the situation where the total number of participants was fifty-three (53) rather than fifty-two (52) as three (3) organizations each had thirteen (13) participants while one (1) organization had fourteen (14)

participants.

The development of quadrants within the organization is consistent with the concern with variation in levels of commitment to values evident in the literature, such as associated with person-centered planning, between the leadership and direct implementers within the organization--the horizontal delineation within the organization. Additionally, the vertical aspect of the quadrants is an effort to examine commonalties and variances between organizational members most directly involved with consumers and those members most involved in supporting the operations of the organization.

Table 1

Organization: Quadrant Delineation

Quadrant 1: Leadership/Direct	Quadrant 3: Leadership/Indirect
Sub Quadrant A: Leadership	Sub Quadrant A: Leadership
Sub Quadrant B: Direct	Sub Quadrant B: Indirect
Quadrant 2: Line/Direct	Quadrant 4: Line/Indirect
Sub Quadrant A: Line	Sub Quadrant A: Line
Sub Quadrant B: Direct	Sub Quadrant B: Indirect

As presented in Table 1, organizations are defined across four major quadrants with two sub-quadrants contained

within each quadrant. Quadrants 1 and 2 contain the organizational members defined as those in closest proximity to persons receiving supports and services; thus these individuals are identified as "direct." Quadrants 3 and 4 contain organizational members who provide support to the operations of the organization; thus these individuals are identified as "indirect." An examination of quadrants 1 and 2 in relationship to quadrants 3 and 4 would yield a comparison between the vertical arrangements of the organization.

Quadrants 1 and 3 contain organizational members who are responsible for establishing the direction of the agency as well as management; thus these individuals are identified as "leadership." Quadrants 2 and 4 contain organizational members who are responsible for the implementation of the agencies direction, thus, these individuals are identified as "line." An examination of quadrants 1 and 3 in relationship to quadrants 2 and 4 would yield a comparison between the horizontal arrangements of the organization. Additionally, an examination of each of the four quadrants in relationship to each of the other quadrants would provide a perspective relative to variances between each of the quadrants.

Table 2

Description and Organizational Placement of Participants

Quadrant 1 (N = 12)	Quadrant 3 (N = 8)
Board Member (N = 4)	Finance Director (N = 4)
Executive Director (N = 4)	Administration Management Related (N = 4)
DD Leadership Related (N = 4)	
Quadrant 2 (N = 21)	Quadrant 4 (N = 12)
Supports Coordinator (N = 21)	Administrative Support Related (N = 12)
Employment Training Specialist (N = 1)	

Table 2 provides a summary overview of the number and types of participants as placed in the organizational quadrants. Quadrant 1 makes reference to "DD Leadership Related." These participants were the highest ranking organizational members responsible for leadership and management of supports and services for people with developmental disabilities. Quadrant 3 makes reference to "Administration Management Related." These participants all have key administrative leadership and management responsibilities and include such positions as the Director of Quality Improvement, Contract Management Supervisor and Management Information Director. Quadrant 4 makes reference to "Administrative Support Related." These participants all have

administrative support responsibilities and include such positions as Reimbursement Officer, Administrative Assistant, Accountant and Clerical Staff.

Consent

Three (3) types of consents were secured. First, each of the four (4) selected organizations consented to participate during the participant recruitment stage. Second, the four (4) selected organizations were required to secure the consent of four (4) consumers to allow the researcher to review their support and service plans. Third, at the time of the site visit, the consent of involvement for each individual organizational member participating in the survey and focus group was required.

The consent forms and explanatory letters are included as Appendix B.

DATA COLLECTION

Data collection occurred in two (2) stages and included participants as individuals and as a group as well as organizational resource documents (artifacts). Data collection efforts occurred in December 1999.

Off-Site Data Collection

As presented earlier, at the time of securing consent to participate, each organization was requested to provide the following information to be picked up by the researcher at the time of the site visit (all items to be in their most current form):

1. Organizational Structure and Job Descriptions for each identified position.

2. Organization Vision and Mission Statements and Values.

3. Organization Strategic Plan. In the event that there was no document identified as the organization's "Strategic Plan," a business plan or any other document identified as the organization's plan was sufficient.

4. Select Organization Policies, Procedures, and Practice Protocols. These are related to the development, implementation, and monitoring of support and service plans and the use of organizational financial resources and consumer access to said resources (e.g., vouchers, personal budgets, flexible funds).

5. Other Reports. These include summary Total Quality Management (TQM) Reports for the past year. In the event that there were no documents identified as the organization's "TQM Report(s)," any other organizational report that speaks to process improvements, performance,

and/or outcomes as related to the organization was sufficient. Additionally, the most recent organization Annual Report as well as any most recent accreditation and/or state agency oversight reports and a description of the organization itself (e.g., purpose, history, legal arrangement, budget, resource arrangements) were requested.

6. Client Plans. A total of four (4) cases of clients with mental retardation were secured. If possible, one (1) case each for an individual with profound, severe, moderate, and mild mental retardation were secured. The organization secured consumer consent and removed names. All clients were involved as a participant in the self-determination initiative.

It should be noted that each organization identified the four (4) clients to serve as participants. Clients, as participants, were limited to simply allowing for a review of their plans and required no direct face-to-face contact initiated by the researcher. Thus, there were a total of sixteen (16) client participants involved in this research endeavor.

Within the criteria stated above, the selection of the plans to be used in this research effort was at the discretion of the organizations. The total possible pool of clients was as follows:

1. Organization A: Of a total of 36 clients in the

self-determination initiative, 33 met the criteria of having a primary diagnosis of mental retardation.

2. Organization B: Of a total of 81 clients in the self-determination initiative, 69 met the criteria of having a primary diagnosis of mental retardation.

3. Organization C: Of a total of 20 clients in the self-determination initiative, 20 met the criteria of having a primary diagnosis of mental retardation.

4. Organization D: Of a total of 80 clients in the self-determination initiative, 75 met the criteria of having a primary diagnosis of mental retardation.

The researcher offered reimbursement to the organizations for the cost of copying the materials as well as for postage. Additionally, the researcher offered to reimburse each organization for costs associated with the collection and copying of materials.

With the exception of the organizational structure document and job descriptions, a content analysis of the information was completed with analysis summary information cataloged into a template instrument (Appendix C). This analysis involved identifying values, knowledge, and practice evidence regarding the concepts of self-determination and community inclusion by resource and template items. Values, knowledge, and practice definitions are included in the Specific Aims chapter.

The organizational chart and job descriptions were used to divide the organization into the four quadrants in order to establish a horizontal and vertical perspective of the organization.

On-Site Data Collection

The single day on-site data collection efforts were initiated in early December 1999 and concluded in mid December 1999.

On-site data collection involved two (2) methods:

1. Survey: Pen/pencil instrument was completed by participants with researcher present in the room (Appendix D). Participants were seated in a manner that they could not easily view the responses of other participants. Survey completion was allowed approximately forty-five (45) minutes and occurred just prior to the focus group.

2. Focus Group: Two (2) focus groups were used. The first group, referenced as the client direct focus group, consisted of the eight (8) participants from the organization quadrants #1 and #2 (client support and service related). The second group, referenced as the client indirect focus group, consisted of the five (5) participants from the organizational quadrants #3 and #4 (organization operations related). Thus, there were two (2) separate focus groups arranged relative to the vertical split of the

organization.

Separately, each of the focus groups discussed ten (10) items (Appendix E). Following completion of the survey, a five (5) minute break was allotted. The client direct focus group then took sixty-five (65) to seventy-five (75) minutes to complete the focus group questions. This process was then repeated with the client indirect focus group.

The researcher and research assistant served as the co-facilitators and scribes. The participants were seated in a circle and the researchers were standing facilitating discussion and scribing on a newsprint visible to all of the participants. The researchers kept discussion on each topic to no more than an approximate average of seven (7) total minutes. The facilitators were also responsible for making efforts to best assure participation by all.

The use of the researcher and research assistant was intended to increase inter-rater reliability. Immediately following the completion of the focus group efforts at each organization, the researcher and research assistant met to debrief. The debriefing focused on identifying shared perceptions as well as identifying and reconciling differences necessary to complete the preparation of the focus group information for organization and analysis.

Following the completion of the on-site data collection efforts, a letter was sent to each organization director

thanking them for their participation and offering to visit their organization to present findings and gain their reaction to the findings and analysis (Appendix F).

INSTRUMENTS

Instruments described in the sections that follow are intended to accommodate the three (3) methods applied: (a) content analysis of organizational artifacts, (b) survey of organizational members, and (c) focus group of organizational members.

Content Analysis Template

The organizational artifacts were organized into a forty-nine (49) content item by nine (9) resource template intended to catalogue information regarding the values, knowledge, and practices of the organization (Appendix C). Items #1 through #30 are derived from The Council (accrediting body) Outcome Based Performance Measures and cover nine (9) subscales. Items #31 through #49 are related to self-determination practices and community-inclusive outcomes and cover five (5) subscales. The template subscales are described in Table 3.

Table 3

Content Analysis Template Organization and Description

Subscale	#'s	Description
Personal Goals	1, 2	Item 1 serves as a proxy to self-determination and item 2 serves as a proxy to community inclusion.
Choice	3, 4, 5, 6, 7	Items 6 and 7 serve as a proxy to self-determination and items 3, 4, and 5 serve as a proxy to community inclusion.
Social Inclusion	8, 9, 10	Proxy to community inclusion.
Relationships	11, 12, 13	Proxy to community inclusion.
Rights	14, 15, 16	Proxy to self-determination.
Dignity and Respect	17, 18, 19, 20	Items 17 and 20 serve as a proxy to self-determination and items 18 and 19 serve as a proxy to community inclusion.
Health	21, 22	Proxy to self-determination.
Environment	23, 24, 25	Item 23 serves as a proxy to self-determination and items 24 and 25 serve as a proxy to community inclusion.
Security	26, 27, 28	Item 28 serves as a proxy to self-determination and items 26 and 27 serve as a proxy to community inclusion.
Satisfaction	29, 30	Item 29 serves as a proxy to self-determination and item 30 serves as a proxy to community inclusion.

Table 3 (cont'd).

Subscale	#'s	Description
Planning Meeting Organization	31, 32, 33, 34, 35, 36, 37	Self-determination practice requirements that the consumer determine when, where, how often, and who will attend their planning meetings as well as the roles of the non-professional participants, including the selection of a spokesperson (as applicable).
Planning Meeting Characteristics-Self-Determination	38	Self-determination practices as they speak to planning meetings being focused on the desires of the consumer.
Planning Meeting Characteristics-Community Inclusion	39	Community-inclusive outcomes as they speak to exploring alternative opportunities in response to potential life experience limitations.
Community Inclusion	40, 41, 42, 43, 44, 45, 46	Community inclusion as they speak to outcomes and opportunities regarding community living, employment and socialization.
Resource Command	47, 48, 49	Self-determination practices as they speak to the consumer's control over financial and human resources relative to the provision of supports and services.

The resource items in the template are described in the Off-Site Data Collection section of this chapter.

The intent of the template was to measure the organization's values, knowledge, and practices with regards to self-determination and community inclusion as defined through organizational content resources (research question #2--between the vertical organization and research question #3--across the horizon of the organization). The categorization into values, knowledge, or practice was dependent on the detail provided within each organizational artifact.

"Characteristics" are defined as:

1. Identifying technical and substantive evidence related to self-determination and community inclusion.

2. Evaluating the evidence to determine if it is conducive to or detracts from self-determination or community inclusion.

3. Identifying the evidence as value-, knowledge-, or practice-related.

4. Cross-referencing consistencies and inconsistencies within the evidence.

In order to establish inter-rater reliability, one (1) graduate social work research assistant was involved in categorizing the information into the template. The researcher first trained the research assistant in the

concepts of self-determination and community inclusion using the literature review as the foundation for the substantive learning of these concepts. The researcher also provided some technical training in the area of content analysis method using resources used in academic learning of said methods. Furthermore, the researcher provided training on the specific operational methodological detail of this research effort necessary for completing the template. Additionally, the researcher provided the research assistant consultations in response to technical questions throughout the process.

The researcher and research assistant separately reviewed and compiled the information into the template as qualitative information in preparation for analysis. At the completion of their individual efforts, the researcher and research assistant met to discuss and resolve differences in an effort to organize information into a final, reconciled template product.

Survey

A survey entitled "Support and Service Practices for People with Developmental Disabilities/Mental Retardation Survey" (Appendix D) was completed by the organizational member participants. This survey instrument is comprised of six (6) components as described in the following sections.

Introduction

The introduction section provides general instructions and assurances of ethical safeguards.

Closed-Ended Survey

The closed-ended survey involved the use of a thirty-four (34) item, three (3) subscale, six (6) point ordinal scale survey instrument intended to (a) measure the participant's perspective regarding the manner in which the organization in which they are a member pursues or fails to pursue practices and outcomes consistent with self-determination and community inclusion, and (b) measure the participant's perspective regarding the manner in which the participant believes the organization should operate as related to the pursuit/non-pursuit of practices and outcomes consistent with self-determination and community inclusion. The subscales are described in Table 4.

Table 4

Closed-Ended Survey Organization and Description

Subscale	#'s	Description
Planning Meeting Organization	1, 2, 3, 4, 5, 6, 7	Self-determination practice requirements that the consumer determine when, where, how often, and who will attend their planning meetings as well as the roles of the non-professional participants, including the selection of a spokesperson (as applicable).
Role of Professionals	8, 9	Self-determination practices as they speak to the role and function of professionals involved in planning meetings.
Planning Meeting Characteristics-Self-Determination	10, 11, 12, 15	Self-determination practices as they speak to planning meetings being focused on the desires, abilities, and rights and responsibilities of the consumer and with problem solving intended to resolve barriers to the pursuit of their desires.
Planning Meeting Characteristics-Community Inclusion	13, 14, 16, 21	Community-inclusive outcomes as they speak to consider accommodation and support needs for natural community participation, exploring alternative opportunities in response to potential life experience limitations, and reasonableness in addressing legitimate health and safety issues.
Plan Characteristics-Central Theme	17	Self-determination practices as they speak to the plan reflecting the desires as defined by the consumer.

Table 4 (cont'd).

Subscale	#'s	Description
Plan Characteristics-Community Inclusion	18, 19, 20	Community inclusion as they speak to the plan addressing outcomes related to the consumers quality of life and pursuing reciprocal relationships with ordinary people and natural places in the community.
Resource Command	22, 23, 24, 25	Self-determination practices as they speak to the consumer's control over financial and human resources relative to the provision of supports and services.
Community Inclusion	26, 27, 28, 29, 30, 31, 32, 33, 34	Community inclusion as they speak to outcomes and opportunities regarding community living, employment, and socialization.

The intent of this part of the survey was to measure the organization's knowledge and practices with regards to self-determination and community inclusion (research question #2--between the vertical organization and research question #3--across the organization).

The closed-ended survey items allowed for participants to respond to two scales for each item. The first scale asked participants to rate the item related to the manner in which the organization was currently operating while the second was related to the manner they believed the organization should operate.

There were two reasons why an inquiry was made regarding the manner in which the organization should operate. First, there was a desire to best ensure that the participants did not confuse their responses between the manner in which the organization operated and how they perceived the organization should operate in responding to a single scale. Thus, the scale is deliberate in having the participants clearly separate these two perspectives to best ensure an accurate portrayal of how they perceived the organization was currently operating. Second, there was a desire to examine any variation in the manner that participants portrayed how they believed the organization should operate. It would be expected that these items would score high and have virtually no variance. This would suggest agreement on the most appropriate manner

the organization should be operating if they were acting in a manner most consistent with the concepts of self-determination and community inclusion. This expectation was verified in that the mean scores were high on these items with virtually no variability. Only the responses related to the manner in which the organizations were currently operating were used in this study (thus, these are the data reported in the Findings chapter).

Open-Ended Survey

The open-ended survey is composed of ten (10) items requiring brief narrative responses by individual participants, which augmented the contributions provided in the focus group. The items are described and categorized in Table 5.

Table 5

Open-Ended Survey Organization and Description

Subscale	#'s	Description
Self-Determination	1, 2, 3, 4, 5	Development of a definition, identification of the essential elements, ethical challenges, barriers in the application, and opportunities in the application of self-determination.
Community Inclusion	6, 7, 8, 9, 10	Development of a definition, identification of the essential elements, ethical challenges, barriers in the application, and opportunities in the application of community inclusion.

The intent of this part of the survey was to measure the organization's values, knowledge, and practices (as contributing to or detracting from) with regards to self-determination and community inclusion as defined by the individual participants (research question #2--between the vertical organization and research question #3--across the horizon of the organization). The categorization into values, knowledge, or practice was dependent on the responses provided by the participants.

Personal Characteristics

The intent of this section was to gather factual information regarding typical demographic information and

personal proximity of the participant to persons with disabilities. This part of the survey was intended to provide data relative to key personal characteristics of the participants to be considered with all three (3) research questions.

Professional Characteristics

The intent of this section was to gather factual information regarding the participant's current employment position and duration in said position, duration with the organization, past experiences and duration in working with people with developmental disabilities as well as human services, college, and other relevant professional training (with specific focus in the areas of self-determination, person-centered planning, and community inclusion). This part of the survey was intended to provide data relative to key professional characteristics of the participants to be considered with all three (3) research questions.

Coding

Coding was completed by the researcher (participant identifiers: organization as well as individual). Coding was completed in such a manner as to distinguish individual participants by organization as well as by organizational quadrant. The organizational code number included a single

digit as uniquely related to each of the four (4) organizations (1, 2, 3, or 4) and the next two (2) digits as uniquely related to the four (4) quadrants (01, 02, 03, or 04). The participant code number was a numerical-unique identifier-sequence as applied to each of the fifty-three (53) participants (01 through 53, inclusive). Scale data was entered in the numeric value as it appeared on the scale while all other information collected were converted into numeric values for data entry.

Focus Group

As indicated in the survey presentation, one (1) survey section provides ten (10) items that serve as the focus group discussion items. The intent of the focus group is to measure the organization's values, knowledge, and practices (as contributing to or detracting from) with regards to self-determination and community inclusion as defined by the collective participants (research question #2--between the vertical organization). The categorization into values, knowledge, or practice was dependent on the responses provided by the participants. A list of the focus group items are provided as Appendix E.

Data Collection Methods Relevance to Research Questions

The research questions and corresponding data collection methods are described as follows:

1. Research Question #1: Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion? The content analysis served as the primary method for gathering data and information for developing a response to this question. The organizational artifacts (key source documents) provided a conceptual and operational description of the manner in which the organization formally operates (as intended and/or as actual). The focus groups provided evidence relative to this question through their verbally communicated representation of the formal organizational system.

2. Research Question #2: Between the direct and indirect organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concept of self-determination and community inclusion? The survey and focus groups served as the primary methods for gathering data and information for developing a response to this question. The survey collected information in a manner that distinguished between direct and indirect organizational members with two focus groups conducted at each site: one group of direct participants and one group of indirect participants. Both

methods gathered pertinent information and data relative to the participants' perceptions and understanding of each concept (self-determination and community inclusion).

3. Research Question #3: Between leadership and line organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concepts of self-determination and community inclusion? The survey served as the primary method for gathering data and information for developing a response to this question. The survey collected information in a manner that distinguished between leadership and line organizational members. This method gathered pertinent information and data relative to the participants' perceptions and understanding of each concept (self-determination and community inclusion).

Research Contributors

A brief biographical overview of the research contributors serving in the roles of Technical and Content Editors, Research Assistant, Focus Group Co-Facilitator, and Statistical Consultant are provided as Appendix G.

University Approval

This research effort was approved by the Michigan State University (MSU) University Committee on Research Involving

Human Subjects (UCRIHS) as provided in Appendix H.


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THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE PURSUIT OF COMMUNITY-INCLUSIVE OPPORTUNITIES AND EXPERIENCES FOR PEOPLE WITH MENTAL RETARDATION

VOLUME II

By

Richard James Visingardi

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CHAPTER 4: FINDINGS

The findings are presented in the following manner:

1. Participant Characteristics: Compiled from surveys completed by the participants. Provides a description of key demographic and relevant personal and professional characteristics of the participants.

2. Content Analysis: Compiled from select organization source documents. Provides a basic understanding of how the organizations formally describes planning, implementation, application, monitoring, and evaluation of the concepts being studied.

3. Focus Groups: Compiled from focus group sessions. Establishes a qualitative perspective relative to (a) accuracy between the responses of the focus groups and the concepts being studied, and (b) consistency of the responses between the direct focus group participants and the indirect focus group participants.

4. Self-Determination and Community Inclusion Scale: Compiled from surveys completed by the participants. Provides a quantitative examination of differences within and between organizations relative to the concepts being studied.

The organizations are presented in the findings as alpha letters A through D (inclusive). It should be noted

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that the sequence does not match the ordering of the organizations that was presented in the Methods chapter. The change in the order is intended to further protect the identity of the organizations. It should also be noted that the term "client" is used throughout this chapter in describing people with developmental disabilities receiving supports and services. There are other terms that could be used (e.g., consumer, citizen with a developmental disability, customer). The consistent use of the single term "client" is intended to apply a single acceptable term describing people with mental retardation in order to prevent confusion.

The Methods chapter provides detailed information regarding the organizational quadrants. A brief summary is offered as follows:

1. Leadership/Direct: Board members, executive directors, and lead manager for programs for people with developmental disabilities.

2. Line/Direct: Supports coordinators.

3. Leadership/Indirect: Chief of finance and other management level administrative support staff (e.g., contract management supervisors, recipient rights officers, management information directors).

4. Line/Indirect: Non-management administrative support staff (e.g., contract managers, accountants, clerical

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In some instances the organizations are delineated between "direct" and "indirect" or "leadership" and "line." "Direct" is a compilation of quadrants one (1) and two (2) and "Indirect" is a compilation of quadrants three (3) and four (4) and represent the vertical organization. "Leadership" is a compilation of quadrants one (1) and three (3) and "Line" is a compilation of quadrants two (2) and four (4) and represent the horizontal organization.

The organizations involved in this study are individual entities; however, they are examined both separately and collectively. The purpose of this study was not to compare differences between the organizations involved. There was a need to establish the nature of commonality and divergence between the organizations in order to determine the ability to treat the data in a collective manner. Thus, the findings are presented as related to both the individual organizations as well as a single assembly of organizations. Although differences between these organizations would be expected, and indeed were apparent, it is reasonable to propose, and was ultimately supported, that the differences were minimal. The focus of this research effort was on the RWJ component of the organizations; a sub-system within each organization which were all of the same intent and of similar duration, size and scope.

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As presented in the Specific Aims chapter, the key research questions being examined are as follows:

1. Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion?

2. Between the direct and indirect organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concept of self-determination and community inclusion?

3. Between leadership and line organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concepts of self-determination and community inclusion?

PARTICIPANT CHARACTERISTICS

Participant characteristics data were compiled from the surveys completed by the participants. These characteristics include basic demographics as well as personal and professional information. Personal information is concerned with the participants' proximity to disabilities (e.g., does the individual have a disability and/or does a family member have a disability). Professional information is focused on the employment and educational history of the participant as

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Table 6

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The participant characteristic information that follows is presented and/or discussed by both organization as well as the organizational quadrants.

Table 6

Participant Gender by Organization

Organization	N	P	Female	P	Male	P
A	13	24.5%	10	76.9%	3	23.1%
B	13	24.5%	8	61.5%	5	38.5%
C	14	26.4%	7	50.0%	7	50.0%
D	13	24.5%	10	76.9%	3	23.1%
Total	53	99.9%	35	66.0%	18	34.0%

As illustrated in Table 6, a majority of the participants (35 of 53) were female. In examining gender by organization quadrants, 68.6% of the participants identified as non-leadership staff were female and 31.4% were in leadership roles while males were divided equally between leadership and non-leadership roles.

Of the fifty-three (53) participants, forty-nine (49) reported their race as "white." The three fringe-rural organizations reported 100% "white" while the single

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Table 7

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urban/suburban organization reported nine (9) "white," three (3) "black" and one (1) "hispanic."

Table 7

Participant Age by Organization

Organization	N	M	Mdn	SD	Min.	Max.
A	13	40.0	40	13.64	23	63
B	13	41.1	41	8.52	29	61
C	14	45.6	49	9.19	27	57
D	13	43.6	42	10.72	27	72

The mean age between organizations ranged from a low of 40.0 to a high of 45.6 (Table 7). The organizations by quadrants revealed a mean age of 53.0 for the leadership/direct participants (CEOs, Board Members, Program Managers) and a mean age of 45.8 for the leadership/indirect participants (CFOs, administrative management staff). The line/direct (client support coordinators) mean age was 35.8 and the line/indirect (non-management administrative staff) mean age was 42.2. There is a 17.2 mean age difference between participants in the direct quadrants (CEOs, Board Members, Program Managers, client support coordinators) and a 3.6 mean age difference between participants in the indirect quadrants (CFOs, administrative management staff,

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Table 8

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non-management administrative staff). Overall, the mean age for leadership participants (CEOs, Board Members, Program Managers, CFOs, administrative management staff) was 50.1, and 38.1 for line participants (client support coordinators, non-management administrative staff).

Table 8

Participant Disability Proximity by Organization

Organization	N	P	Self	P	Family Member	P
A	13	24.5%	2	15.4%	8	61.5%
B	13	24.5%	1	7.7%	10	77.0%
C	14	26.4%	1	7.1%	8	57.1%
D	13	24.5%	2	15.4%	6	45.2%
Total	53	99.9%	6	11.3%	32	60.4%

The survey included two items that listed nine (9) categories of cognitive, mental, physical, and health related disabilities, inquiring if the participant and/or one of their family members had been diagnosed with a disability. "Family member" included persons living as well as deceased who are/were defined as the participant's partner (spouse, living together romantic partner), child, parent, and/or sibling. As presented in Table 8, a total of

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six (6) participants reported they had been diagnosed with at least one disability while thirty-two (32) reported that at least one of their family members had been diagnosed with at least one disability. Thirty-eight (38) or 71.7% of the participants have a close proximate relationship to disabilities in their personal lives.

Table 9

College Degree by Organization Quadrant

Quadrant	N	None	A	B1	B2	M1	M2	PhD
Leadership/Direct	12	2	2	9	1	8	1	0
Leadership/Indirect	8	0	5	5	1	2	0	1
Line/Direct	21	3	4	18	1	2	0	0
Line/Indirect	12	3	3	7	1	2	1	0
Total	53	8	14	39	4	14	2	1

Key: A = Associates Degree; B1 = Bachelors Degree; B2 = Second Bachelors Degree; M1 = Masters Degree; M2 = Second Masters Degree

Table 9 presents information regarding college degrees earned by the participants. A total of eight (8) participants reported they had not earned a college degree. Five (5) of the eight (8) associates degrees earned by participants in the leadership/indirect and line/indirect

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quadrants are business administration and/or management related. Of the eight (8) participants in the leadership/indirect quadrant, five (5) reported they had earned at least one bachelors degree with three (3) participants earning a graduate degree (two masters degrees and one Ph.D.). Seven (7) of the twelve (12) participants in the line/indirect quadrant reported they had earned at least one bachelors degree with two (2) earning at least one masters degree. Nine (9) of the twelve (12) participants in the leadership/direct quadrant reported they had earned at least one bachelors degree while eight (8) participants in this quadrant reported they had earned at least one masters degree. Eighteen (18) of the twenty-one (21) line/direct quadrant participants reported they had earned at least one bachelors degree.

Fifteen (15) of the eighteen (18) bachelors degrees held by participants in the line/direct quadrant are in the areas of psychology, social work, or sociology. Five (5) of the masters degrees held by participants in the leadership/direct quadrant are in social work (2) or psychology (3).

A total of four (4) participants hold a second bachelors degree (one in each of the four organization quadrants) while two (2) participants hold a second masters degree (one each in the leadership/direct and line/indirect

quadrants).

Table 10

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Table 10

Years Employed in Current Job by Organization Quadrant

Quadrant	N	M	SD
Leadership/Direct	12	6.87	4.39
Leadership/Indirect	8	6.02	4.66
Line/Direct	21	4.25	3.20
Line/Indirect	12	4.61	3.58

Table 10 provides information regarding the number of years the participants have been employed in their current employment position. As evident in the table, leadership participants reported a longer average duration in their current position in comparison to line participants. Further examination within the two groups shows an overall leadership duration in current position mean at 6.47 and an overall line duration in current position mean at 4.39. Additional comparison between the overall direct participants and the overall indirect participants finds very little difference in average duration in their current position (direct M = 5.06, indirect M = 5.18). A comparison of means between the organizations finds Organization A with the shortest average duration in current position (M = 4.27)

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Table 11

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Table 11

Years Employed with the Organization by Organization Quadrant

Quadrant	N	M	SD
Leadership/Direct	12	9.55	5.76
Leadership/Indirect	8	12.10	8.65
Line/Direct	21	5.25	3.79
Line/Indirect	12	6.87	4.89

Table 11 provides information regarding the number of years the participants have been employed with the organizations. Similar to the findings related to current employment duration, overall leadership participants reported a longer average duration of employment with the organization (M = 10.75) in comparison to overall line participants (M = 5.86). Also, the overall indirect participants reported a longer average employment duration with the organization (M = 8.96) as opposed to the overall direct participants (M = 6.59). Organization B had the shortest employment duration (M = 5.93) while Organization D had the longest (M = 9.22).

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Table 12

Years Employed Working with People with Developmental Disabilities by Organization Quadrant

Quadrant	N	M	SD
Leadership/Direct	12	16.676	9.0157
Leadership/Indirect	8	13.875	7.2823
Line/Direct	21	8.721	5.7316
Line/Indirect	12	9.118	7.9502

Table 12 provides information regarding the number of years the participants have been employed working with people with developmental disabilities. Overall leadership participants reported a longer average duration in working with people with developmental disabilities (M = 15.36) in comparison to overall line participants (M = 8.87). Very little difference was found in mean years of employment working with people with developmental disabilities between direct (M = 11.19) and indirect (M = 11.02) participants. Among the four (4) organizations, mean years of employment working with people with developmental disabilities was shortest for Organization D (M = 8.42) and longest for Organization C (M = 12.56).

Table 13

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Table 13

Relevant Substantive Training by Organization Quadrant

Quadrant	N	PCP	S-D	CI
Leadership/Direct	12	8	8	6
Leadership/Indirect	8	6	7	3
Line/Direct	21	21	20	13
Line/Indirect	12	6	5	3
Total	53	41	40	25

Key: PCP = Person-Centered Planning; S-D = Self-Determination; CI = Community Inclusion

Table 13 provides a summary of training attendance relevant to person-centered planning (PCP), self-determination (S-D), and community inclusion (CI). Participants were asked if they had any formal training in the past two years. "Formal training" was defined as a technical and/or substantive training in the specific area that was (a) a planned event, (b) conducted by an expert in the area, and (c) was at least four hours in duration. As evident in the table, all of the line/direct participants reported training in person-centered planning while all but one of the line/direct participants reported training in self-determination. The least reported training for each of the quadrants was in community inclusion while the

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line/indirect participants proportionately reported the least amount of training in all three areas.

Summary of Participant Characteristics

In developing a general profile of the participants, they would be described as mostly female (over 66%), white (over 92%), and ranging in age from 23 to 72 ($\underline{M}$ = 42.6). The number of males in leadership roles were proportionally greater. Approximately 74% of the participants reported they had earned at least one bachelors degree and over 15% reported they had not earned a college degree. Proportionally more line/direct participants had received at least one intensive training in person-centered planning, self-determination, and community inclusion as compared to any of the other three groups. Six (6) participants reported they had a cognitive, mental, or health related disability; however, just over 60% reported they had at least one family member with such a disability and over 71% reported a close personal proximity to disabilities. Leadership participants were, on average, employed longer in their current job position, employed with the organization longer, and worked with people with developmental disabilities longer as compared to line participants. Leadership participants were also older than the other participants.

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CONTENT ANALYSIS

The purpose of the content analysis was to examine the research inquiry as to the larger organizational structure as contributing to or detracting from practices conducive to self-determination and community inclusion. This required an examination of source documents describing the organization's planning, implementation, application, monitoring, and evaluation efforts. This also required an examination on two levels: (a) the organization as a macro entity (e.g., vision, mission, values), and (b) the organization's specific practices related to self-determination and community inclusion (e.g., relevant policies, support plans of clients in the self-determination initiative). As noted above in the Methods chapter, each organization supplied the researcher with a variety of organizational source documents which included the most recent support plans for four (4) clients involved in the RWJ sponsored Self-Determination initiative.

As described in the Methods chapter, source documents were reviewed by two researchers working independently. The researchers organized evidence (information contributing to as well as from the concepts) into a template framed with forty-nine (49) indicators. These indicators were intended to structure the content analysis in a manner that would ensure comprehensive coverage of the two focal concepts of

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this research effort (self-determination and community inclusion). These indicators were organized into the summary of subscales identified in Table 14 (as briefly summarized and derived from the Methods chapter).

Table 14

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Personal Goals
Choice
Social Inclusion
Relations
Rights
Dignity a Respect
Health
Environme
Security
Satisfact

Table 14

Content Analysis Template

Subscale	Community Inclusion Indicators	Self-Determination Indicators
Personal Goals	Realize	Choose
Choice	Where/who live with; where work; use of free time	Services; daily routine
Social Inclusion	Participate in community; interact with others; perform social roles	
Relationships	Friends; natural supports; intimate relationships	
Rights		Exercise rights; due process; free from abuse and neglect
Dignity and Respect	Privacy; personal possessions	Respected; decide who to share information with
Health		Health services; best possible health
Environment	Use; integrated	Safe
Security	Have economic resources; insurance	Continuity and safety
Satisfaction	Life situation	Services

Table 14

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Planning Meeting Organizat
Planning Meeting Character istics
Planning Meeting Character istics
Community Inclusion
Resource Command

Table 14 (cont'd).

Subscale	Community Inclusion Indicators	Self-Determination Indicators
Planning Meeting Organization		Decide invitees, location, time, frequency, facilitator, spokesperson(s)
Planning Meeting Character-istics		State desires
Planning Meeting Character-istics	Opportunities to explore new life experiences	
Community Inclusion	Supported living, employment; choose career; natural socialization; accommodated, supported; planned real life outcomes	
Resource Command		Choose providers; hire and fire; control of purchase funds

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Interater agreement was reached by reconciling the independent researchers' efforts into a single reconciled set of qualitative findings. The qualitative content evidence was then organized for presentation as follows:

1. Planning and Implementation: Source documents including the organizations' statements of vision, mission, and values; plans; goals and objectives; and relevant policies, procedures, and practices.

2. Monitoring and Evaluation: Source documents that are internal (e.g., quality management reports) or external (e.g., accreditation reports, state or local public entity oversight reports) monitoring and/or evaluation reports. Although some attention is given to the substantive nature of monitoring and evaluation findings, the main focus of the analysis was to find evidence that the organization was actually conducting relevant monitoring and evaluation activities.

3. Application: Client support plans. Evidence is presented that reflects practices of the concepts. Client support plans are presented as case scenarios.

Information about each organization was examined separately. Additionally, the information was examined in two ways: (a) the extent to which evidence (favorable as well as unfavorable) is present, and (b) the degree of consistency among the three domains--planning and

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implementation, monitoring and evaluation, and application. These domains provide a perspective regarding the manner the systems organize (plan and implement), oversee (monitoring and evaluation) and practice (apply) the self-determination and community inclusion concepts.

In developing a perspective for analysis, a consideration of best practice was included. For each of the three areas (planning and implementation, monitoring and evaluation, and application) there are specific items of evidence that would suggest best practice and an exemplary organization. The following provides a brief description of best practice related evidence:

1. Planning and Implementation: Client-focused and driven; client treated with dignity and as a full citizen; access to resources available in the community and opportunities to participate as a regular community member; leadership and organizational members committed to and resources allocated for the concepts of self-determination and community inclusion; movement away from service-delivery programs to support-oriented models of practice; support and accommodation philosophy and practice; mechanisms to ensure person-centered planning and client resource control.

2. Monitoring and Evaluation: Continuous quality improvement efforts evident with focus on process improvements intended to better achieve outcomes related to

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community inclusion (e.g., supported living, supported employment), quality of life (e.g., variety, durability, number of relationships with natural places and ordinary people in the community), customer satisfaction and client control (e.g., person-centered planning, resource control); substantive findings in oversight efforts (e.g., evaluation of self-determination and community inclusion related efforts).

3. Application: Client selecting where, when, and who will attend person-centered planning efforts; client's desires driving the planning process; exploration of alternatives to traditional service-delivery methods; exploration of opportunities (and supporting the pursuit of said opportunities) that would serve to expand the client's life experience and interactions/development of relationships with ordinary people and natural places in the community; intervention efforts and outcomes reflect pursuit of the client's desires.

Organization A

As presented in Table 15, there was a good deal of planning related information in the goals and objectives area that spoke directly to the community inclusion subscale, particularly as related to employment and housing. Also, the person-centered planning policy and procedure

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included requirements that the client choose when and where the planning meetings were held, who attends, who provides supports and services, etc. Requirements also included that clients' desires, goals, and health and safety issues be addressed and that the plans reflect community inclusion.

Table 15

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Component	
Vision, Mission, Values, Principle and/or Philosoph	
Organizat Plan	
Goals and Objective	
Policies, Practices and Procedur	

Table 15

Organization A: Planning and Implementation

Components	Evidence
Vision, Mission, Values, Principles, and/or Philosophy	Create a community where support is encouraged; work with community organizations and systems; person-centered planning; dignity and respect
Organization Plan	Safety of consumers; recipient rights systems; report of client satisfaction
Goals and Objectives	Continue leadership in the self-determination project; development of individual budgets; movement away from facility-based programs to supports services; person-centered planning; increase rental, home ownership, and supported housing; increase quality and quantity of supported employment/job opportunities; inquiry of satisfaction with jobs secured; clients in workshops exposed to new community experiences
Policies, Practices, and Procedures	Create a community where support is encouraged and available to promote productive lifestyles; provide opportunities for full community participation; based on principles of same citizenship rights; acknowledge the development of interpersonal relationships and sexual expression by consenting adults and personal dignity; invest the client with the authority to control resources available for his/her support; person-centered planning (detailed policy and procedure)

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As described in Table 16, there was particular attention to community-inclusive efforts (e.g., supported employment and supported housing) in both the internal as well as external reports. The referenced client satisfaction survey contained twenty (20) questions that included inquiries as to the clients' life satisfaction as well as satisfaction with person-centered planning efforts and the receipt of supports and services. One external report indicated that client plan documentation did not provide adequate evidence that community-inclusive opportunities were being pursued (e.g., natural support, community-inclusive activities).

Table 16

Organizat

Source
Internal Reports
External Reports

Table 16

Organization A: Monitoring and Evaluation

Source	Evidence
Internal Reports	Quantitative report of goal attainment relative to clients moving into supported living arrangements and supported employment, establishing individual budgets, client initiated community activities, and report of satisfaction with supports and services; description of organizational efforts in developing supported work opportunities, movement away from segregated workshops, creating community opportunities (e.g., volunteering, group memberships); summary report of client survey of satisfaction
External Reports	Commended on care and attention to preserving human rights of clients, dignity and respect, clients reaching vocational goals, and health and safety systems; identified evidence of clients driving job placement decisions; clients identified desires being addressed in person-centered planning--however, plans lacked documented evidence of the identification of natural supports, community-inclusive activities, and the clients' dreams and desires

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There was a good deal of consistency between the planning/implementation efforts and monitoring/evaluation activities, particularly as related to community inclusion. For example, consistent with the vision to create a community where support is encouraged, (increased) supported employment outcomes were identified in the goals and objectives. Corresponding to these planning and implementation efforts, monitoring involves both efforts in developing new supported work opportunities as well as the number of clients moving into supported employment arrangements.

Table 17

Organiza

Case
Client #
Client #

Table 17

Organization A: Client Plans

Case	Scenario
Client #1	Male. Planning meeting convened at the place client resides. Wants to live with male siblings in his own room or by himself. Wants to feel better, get a job again when physically able, ride a horse and get outside more. Likes being around people, and family is important to him (particularly male siblings). Plan calls for visits to potential places to live to guide decision-making (already visited one place that his brothers may move to), exploration of the community to identify activities, stabilization of emotional and physical well-being (e.g., take meds, follow diet), and better health (exercise). Plan noted that the individual budget had not yet been completed.
Client #2	Male. Planning meeting convened in the client's apartment. Resides in a supported living arrangement and has a job in the community. Desires to drive and own a vehicle (but not at this time), to obtain a new three wheel bike (to get around the community better), and to work different hours at his current place of employment (is waiting for a new time slot to open). Feels comfortable around friends, family, and people from work, church, and several community members. Interested in sports and has participated in Special Olympics (will become more involved with). Individual budget is included in plan. Plan identifies maintaining housing in a manner that is consistent with the apartment complex requirements, a reduction in excessive talking at work, the purchase of a new bike, and participation in social activities.

Table 17

Case

Client #

Client #

Table 17 (cont'd).

Case	Scenario
Client #3	Male. Planning meeting convened in the client's apartment. Residing in a supported living arrangement (planning to move so he can live alone) and recently left the day program (wants assistance in finding a job). Likes helping others, ARC and RICC dances and activities, visiting neighbors, and leisure activities (e.g., snowmobiling, bowling). Very active in church and on two organization-sponsored committees (housing and careers). Wants improved transportation. Has a number of friends (particularly at church) and family members that visit him. Individual budget is included in plan and plan identifies maintaining housing in a manner that is consistent with the apartment complex requirements while getting ready to move in the next few months, and working with staff to find a job.
Client #4	Male. Planning meeting convened in the client's apartment. Residing in a supported living arrangement (recently moved to new apartment complex) and is in a workshop (but would like a job in the community--preference for piece work due to physical disability). Does not have a circle and does not want people to have input in his life. Has limited contact with family, tried to integrate into church but has been strongly opposed (though he continues to go), and has unable to make additional friends. Wants to live alone and likes going to restaurants and shopping (likes to buy pants). Individual budget is included in plan. Plan identifies assistance in contacting landlord when there are problems, assistance in finding a job (or adding to his present job at the workshop), elimination of knocking on neighbors doors unless there is an emergency, and completion of assigned tasks at the workshop.

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Table 17 provides a summary of the client support plans. Three (3) of the four (4) plans provide evidence of residence as a supported living arrangement with all planning meetings being conducted in the clients' homes. There is a good deal of discussion in the plans regarding clients' desires to develop stronger connections to the natural community (e.g., becoming more mobile, getting or maintaining employment, visiting people and developing and maintaining relationships). Individual budgets were included in three (3) of the plans (and was referenced as not yet being included in the one other plan). The client plans; however, revealed a more programmatic intervention approach with a traditional compliance focus (e.g., abiding by apartment complex rules, reducing the amount of talking at work, continuing to go to church even though client is resistant, emotional and physical stability) being somewhat present.

There appears to be consistency, particularly as related to community inclusion, between the planning/implementation and monitoring/evaluation evidence. The client plans; however, indicate inconsistency as compared to the other source documents. Relative to self-determination practices, this is most evident in the plans reflecting traditional interventions typically intended to reduce what is termed as maladaptive behaviors. Organization

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Organization B

As presented in Table 18, self-determination was comprehensively described through a policy and corresponding set of procedures and practice protocols. Considerations included person-centered planning (which was in addition to the organization's general policy with regards to personal planning policy), individual budgets, and principles of self-determination (e.g., relationships, contributions to the community; roles and responsibilities; control; dreaming, dignity and respect, and doing "whatever it takes"). Additionally, and as related to self-determination, the organization has a fiscal intermediary arrangement that provides a mechanism for clients to hire and fire support staff. There was also substantive reference to community inclusion (e.g., client as part of community workforce, support for inclusion).

Table 18

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Table 18

Organization B: Planning and Implementation

Components	Evidence
Vision, Mission, Values, Principles, and/or Philosophy	Enable clients to experience a full life with dignity, health, opportunity for personal growth and self-esteem while residing in the community; recognition of client as a full citizen; regardless of disability, clients can be part of the community workforce; right to typical housing; participate in the identification of services and supports; family as a constant in clients' lives; integrated living (e.g., friendships, responsibilities, community contributor)
Organization Plan	Task group charged with improving process to help clients achieve personal outcomes; development of supported employment options; development of natural supports (e.g., relationships and community involvement); inclusion of housing choice in client plans
Goals and Objectives	Support for inclusion and community integration
Policies, Practices, and Procedures	Agreement with an external entity serving as a fiscal intermediary; description of self-determination practices; client satisfaction process; client right to choose who to live with and where to live; description of personal planning

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The single-subject evaluations identified in Table 19 were conducted as part of an improvement effort. Following the organization's accrediting body review of these client plans, the organization described efforts to make improvements in deficient areas. One year following the accreditation review, the organization applied the same standards and methods in evaluating the client plans.

Table 19

Organization B: Monitoring and Evaluation

Source	Evidence
Internal Reports	Quantitative report of goal attainment relative to clients moving into supported employment; description of efforts to promote natural supports development and community inclusion as part of client circle development; single-subject evaluations of the achievement of personal outcomes of three clients
External Reports	Note: Accreditation Report was covered, in part, in the plan section

The level of consistency between the planning/implementation and monitoring/evaluation activities was difficult to ascertain. This is attributed to the lack of source documents. A greater amount of attention was paid to the planning/implementation efforts as compared to the monitoring/evaluation practices. However, there was evidence

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that suggested some level of consistency (e.g., supported employment; natural supports).

Table 20

Organiz

Case

Client

Client

Table 20

Organization B: Client Plans

Case	Scenario
Client #1	Forty (40) year old male with moderate mental retardation who resides in a licensed residential community facility and is working in the community. Enjoys baseball, attending sporting events with friends, and occasionally going to the bar. Desires (client communicated these verbally) to expand circle of friends, go on a trip to Florida, and move to his own home (none of which have occurred yet). Dissatisfied with the time it is taking to achieve movement into own home. Natural supports include family (with contact to occur "often" for the purpose of familiar support) and friends (with contact to occur "often" for the purpose of social support). Most recent person-centered planning meeting (held at the group home) had seven persons in attendance with five (excluding the client) being described as professional/provider support staff and one person identified as the guardian.
Client #2	Forty-four (44) year old female who resides in a supported living arrangement and is not involved in a day program, supported employment, and/or any other community activity. Enjoys crocheting, doing math workbooks, reading books, and watching TV. Desires (not defined how or if the client communicated these) to improve health (through an exercise routine and help with household chores to increase stamina) and enjoys caring for a flower garden (incorporated as a household chore). All desires being implemented. Will also begin looking at day activities. Natural supports include family (with contact to occur "monthly" for the purpose of familiar support). Most recent person-centered planning meeting (held at the client's home) reflected six persons in

Table 20 (cont'd).

Case	Scenario
	attendance with five (excluding the client) being described as professional/provider support staff.
Client #3	Forty-five (45) year old female with moderate mental retardation who resides with a sibling and is not involved in a day program, supported employment, and/or any other community activity. Enjoys TV and spending time with her sibling that she lives with and friends. Desires (client communicated these by shaking head and communication device) to participate in ARC events, visit friends in licensed community facility, and gardening and yard work (desires status unknown). Not ready to work but will begin looking for work once client desires to do so. Natural supports included family (with contact to occur "daily" for the purpose of familiar support) and friends (with contact to occur "as desired" for the purpose of social support). Most recent person-centered planning meeting (held at the agency) reflected six persons in attendance with four (excluding the client) being described as professional/provider support staff and one identified as a sibling.
Client #4	Forty-four (44) year old female with severe mental retardation who resides in a supported living arrangement (recently moved from mother's home) and attends a day program/workshop. Enjoys TV, music videos, and rides in vehicles. Dislikes the current workshop she is attending, getting up early, and being told what to do. Desires (communicated by "team" with the exception of with weight loss which client shook head indicating "yes") to maintain relationships with family and friends, increase social interactions in the community, search for a new workshop (does not desire to work) and lose weight. Natural supports included family contact to occur "anytime" for the purpose of

Table 2C

Case

Table 20 (cont'd).

Case	Scenario
	(with contact to occur "anytime" for the purpose of familiar support) and friends (with social support). Most recent person-centered planning meeting (location unknown) reflected five persons in attendance with four (excluding the client) being described as professional/provider support staff.

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As evident in Table 20, support plans show marginal natural supports in the lives of the clients (particularly as involved in planning). Additionally, only one of the clients is in a supported employment arrangement. With the exception of one client, descriptions of what the clients' enjoy seem to be primarily solitary activities, which may minimize opportunities to meet people in the community. Some of the stated desires reflect natural routines and community connections (e.g., gardening, going on a trip); however, a number of the desires resemble traditional programmatic goals (e.g., attending segregated activities, weight loss, visiting other people with developmental disabilities, looking for a new workshop).

Planning/implementation related documents yielded the strongest and most accurate description of both self-determination and community inclusion. Client desires were evident in the plans; however, there were only marginal connections with natural supports and inclusive opportunities. On paper, the organization appears to have validity with the concepts of self-determination and community inclusion, but in reality, the organization falls short in the actual application of these concepts.

Organization C

As included in Table 21, the mission statement includes language that may detract from the concept of self-determination. The concept of "care" and "mental health" may be intended for other populations served by the organization (not relevant to people with developmental disabilities, particularly those individuals who are involved in the self-determination initiative). The person-centered planning policy is outcomes-based (e.g., relationships, community connections, gaining respect) and comprehensive as it requires client direction of the process, client capacity-building (e.g., strengths and opportunities for new experiences) and client network development. The organization plan and goals and objectives include a description of community-inclusive efforts such as affordable housing, services being provided in natural settings, and engaging clients in activities that promote community life.

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Table 21

Organization C: Planning and Implementation

Components	Evidence
Vision, Mission, Values, Principles, and/or Philosophy	Integrated system of mental health care; value and dignity of clients; dedication to clients; outcome oriented; use of creativity
Organization Plan	Development of alternative housing for clients moving out of structured residential settings; service plans reflect continuing use of existing natural supports, particularly family systems, or the development of such supports, when indicated
Goals and Objectives	Services to be carried out in the most natural setting; build upon client capacities to engage in activities that promote community life
Policies, Practices, and Procedures	Person-centered planning; individual budgets (as part of person-centered planning); customer satisfaction process; quality improvement guidelines (documentation of outcomes in client plans, such as clients choosing who will attend planning meetings, developing friendships, and going places in the community).

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As evident in Table 22, internal monitoring efforts were primarily focused on managed care related activities (e.g., monitoring penetration rates, inpatient utilization, and outpatient-based client satisfaction). However, the description of the individual budgeting process interface with the utilization management function is designed so that any budget equaling 75% or less than that of the previous year's budget is automatically approved by the utilization management committee. External monitoring efforts indicate some mixed findings regarding person-centered planning. For example, external reviewers generally reported more positive findings resulting from client interviews, whereas the plans themselves were often missing key elements. External reviewers also made recommendations for the organization to develop a more systematic process for monitoring outcomes and to better apply learnings from this process in management decision-making.

Table 22

Organizat

Source
Internal Reports
External Reports

Table 22

Organization C: Monitoring and Evaluation

Source	Evidence
Internal Reports	Quality improvement report contained data required by the public oversight entity with average days between requests and services as the single item related to people with developmental disabilities; description of individual budget and utilization management system
External Reports	Commended for comprehensive recipient rights policies and procedures; recommended that efforts of monitoring outcomes become more systematic and applied; evidence clients were treated with dignity and respect; acknowledged employment services being provided to people with developmental disabilities, support staff as knowledgeable of local job market, and said staff actively seeking natural supports in the work-site post employment; evidence of person-centered planning occurring; community activities based on each client plan--done in small groups; client reported choice regarding person-centered planning participants and location and expression of desired outcomes at the meeting; client reported satisfaction with services; person-centered planning problems (per the documented plan) include desired outcomes not clearly identified, natural supports identified but no description of the specific supports to be provided, and health and safety issues identified but no specifications of how the issues would be addressed

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There was evidence in the reviewed source documents that indicate self-determination and community inclusion are incorporated into the planning/implementation and monitoring/evaluation practices of the organization. However, there is one key potential impediment: the organization has a potential competing and conflicting interest--managed care as it relates to populations other than people with developmental disabilities. Although managing a system of support is not foreign to "managed care," traditional focus (e.g., mental health related) applied to the broader organization could detract from and/or misdirect the pursuit of self-determination practices and community-inclusive outcomes.

Table 23

Organizat

Case
Client #
Client #

Table 23

Organization C: Client Plans

Case	Scenario
Client #1	Fifty-seven (57) year old female with a primary diagnosis of mild mental retardation who resides in a supported living arrangement (moved into own apartment in the past year). Desires to continue living in apartment (identified need to work on housekeeping skills and personal hygiene), obtain a job in the community (with kids, animals, or garden or craft shop), become more integrated in the community (will continue to participate in activity program until acquires "lots of friends"), volunteer in the community, and learn quilting and ceramics. Support services involves teaching housekeeping and laundry skills, meal planning, grocery shopping, cooking dinner, weight management/health monitoring, dog grooming care, and engagement in dating activities. Individual support budget included in plan. Natural supports included male sibling and his wife, people living in the apartment complex (made friends with people at the complex), and other acquaintances in the community.
Client #2	Thirty-three (33) year old female with a primary diagnosis of moderate mental retardation who resides in a licensed residential community facility and is attending a day program. Desires to live in own place with someone to provide daily living assistance, work in the community (dissatisfied with current day program arrangement and not sure what type of job wanted, thus will stay at the day program until a job is developed), go to church and the library, learn to use a computer and play guitar, subscribe to a magazine, and learn more about the community. Each of these desires were included as plan objectives. Individual support budget included in plan.

Table 23

Case

Client #

Client #

Table 23 (cont'd).

Case	Scenario
	Natural supports included mom and friends at the day program.
Client #3	Thirty-four (34) year old male with a primary diagnosis of profound mental retardation who resides in a licensed residential community facility and is attending a day program (identified as not eligible for community employment due to safety issues and functioning level). Enjoys watching TV, stringing beads, coloring, music and interactions with familiar people. Desires to continue living at group home, receive specialized training in the community (to better develop coping skills) and participate in the community (may reduce fear and anxiety). Plan provides supports for in-home programming (e.g., behavior goal to reduce anxiety, ADLs, develop domestic skills and interests) and going into the community to explore new things. Individual support budget included in plan. Natural supports is a male sibling (who recently became involved).
Client #4	Twenty-one (21) year old female with a primary diagnosis of mental retardation and special education certification of EMI who resides in a semi-independent residential program (moved from living with mom in to this arrangement 18 months ago) and is working in the community (has held job for past 12 months and got this job 6 months after graduating from high school). Desires to find a better job and to do things in the community (plan reflects support to help with both of these as well as with what client would like in life). Individual support budget included in plan. Natural supports included mom and aunt and "numerous" friends.

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As presented in Table 23, one (1) of the four (4) clients is in a supported living arrangement. One (1) individual is working; however, two (2) others are looking for employment while one (1) client has been determined too severely impaired to work. Individual budgets were included in each support plan; however, there was no evidence in either direction as to control of the budget. There is good evidence that exploration of the community is being initiated (e.g., simple experiences, inquiries) to determine what types of community activities clients may desire. Some activities in the plans resembled traditional practices (e.g., ADLs, training in domestic tasks, weight management) and there is some question as to whether these were stated as desires by the client (and, if so, did it simply reflect lack of experience).

Planning/implementation and monitoring/evaluation evidence offered substantial and accurate information concerning the organization's understanding ("what should happen") of the concepts of self-determination and community inclusion. These concepts were to a lesser degree present in the plans, as said plans reflected more traditional programmatic intervention approaches (e.g., day and residential programs). Therefore, the organization's descriptions of practices may be more accurately related to self-determination and community inclusion than to actual

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Organization D

As presented in Table 24, the organization has very clearly and accurately conceptualized the fundamental values of self-determination and community inclusion in the source documents that reflect the essential purpose of the organization (e.g., vision, mission). The organization also has a comprehensive person-centered planning policy. The organization's planning efforts include relevant process considerations (e.g., consumer satisfaction inquiry) and outcomes (e.g., maximize clients involvement as community members); although it is undetermined as to whether these have been developed as measurable.

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Table 24

Organization D: Planning and Implementation

Components	Evidence
Vision, Mission, Values, Principles, and/or Philosophy	Clients becoming full participants in community life to the degree desired by each individual; help clients increase control over their lives, achieve dignity and respect, develop and maintain relationships, and realize their potential as vital members of the community; community inclusion
Organization Plan	Survey of customer satisfaction; housing arrangements reflect typical settings in the community; enhance community ability to accept, understand, and accommodate clients; maximize client involvement as community members; apply process of self-determination
Policies, Practices, and Procedures	Person-centered planning policy

As evident in Table 25, the organizations attention to matters of monitoring and evaluation are minimal. The reviewed source documents suggest a lack of empirical evidence necessary to oversee processes and outcomes. Additionally, the system which is intended to provide a method for the organization to engage in continuous quality improvement practices is in the initial stages of development.

Table 25

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Source
Internal Reports
External Reports

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Table 25

Organization D: Monitoring and Evaluation

Source	Evidence
Internal Reports	Note: Quality improvement efforts were covered, in part, in the plan section
External Reports	Review process (e.g., client feedback) not implemented in a number of areas and overall continuous quality improvement system is in the beginning stages; evidence of long-term person-centered planning practices, but not clearly detailed procedurally; frequency of person-centered planning review not included in client plans

There was evidence in the source documents reviewed that indicates self-determination and community inclusion are best incorporated into the broadest planning/implementation practices of the organization (e.g., vision, mission, plan). However, the organization has key shortcomings at the point of procedural guidelines providing direction for application as well as with the systematic efforts necessary for monitoring and evaluation.

Table 26

Organizat

Case
Client #1
Client #2

Table 26

Organization D: Client Plans

Case	Scenario
Client #1	Forty-one (41) year old male with a primary diagnosis of moderate mental retardation who resides in a supported living arrangement and works in a job in the community. "Loves" job and, in the past year, went scuba diving (wants to try it again--looking into going south to do so), went on vacation with family, found a volunteer friend, attended church, secured a roommate, participated in activities offered by the parks and recreation department, and went on vacation. In upcoming year, desires to go to concerts, go on a train ride, and go out-of-state for a visit (all were addressed in the plan). Individual support budget included in plan which included social and community connection considerations (e.g., renting videos, possibility of joining a bike club). Evidence in plan that the client identified who to invite to the planning session, who would serve as the facilitator, developed the agenda and what would be discussed, the date/time and location of the meeting, and the manner in which invitations would be handled. Parents involved and friends identified.
Client #2	Thirty-four (34) year old male with a primary diagnosis of severe mental retardation who resides in a supported living arrangement and works in a workshop setting. Activities the client has done and liked in the recent past include going to see a movie, going to a birthday party, going to a parade, swimming and walking, and buying things (e.g., videos and CDs). Also, is planning to go to a wedding reception. Individual support budget included in plan. Evidence in plan that the client identified who to invite to the planning session, who would serve as the facilitator, developed the agenda and what

Table 26

Case

Client

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Table 26 (cont'd).

Case	Scenario
	would be discussed, the date/time and location of the meeting, and the manner in which invitations would be handled. Parents involved as are a male and female sibling and friends identified.
Client #3	Fifty-one (51) year old male with a primary diagnosis of severe mental retardation who resides in a supported living arrangement and works in a workshop setting. Activities the client has fun doing include going out into the community (helps as he is easily bored), making cookies, interests in specific TV shows, and attending a cooking class (class has been discontinued, thus, plans are being made to increase cooking opportunities in home). Plan calls for providing increased choices in daily routine, allow (in general, as many choices as possible, reduced time in workshop as he has lost interest, going to the barber, starting a photo album, going on drives and walks, and going to cook outs. Evidence in plan that the client identified who to invite to the planning session, who would serve as the facilitator, developed the agenda and what would be discussed, the date/time and location of the meeting, and the manner in which invitations would be handled.
Client #4	Thirty-nine (39) year old male with a primary diagnosis of mild mental retardation who resides in a supported living arrangement and works in an employment setting in the community. Client is content with his life, likes spending time with people and is interested in weather and storm formations and music. Desires include working more at his current job (which he likes very much), a serious relationship with a woman, and enough activities to keep busy. Evidence in plan that the client identified who to invite to the planning session, who would serve as the facilitator, developed the agenda and what

Table 2(

Case

Table 26 (cont'd).

Case	Scenario
	would be discussed, the date/time and location of the meeting, and the manner in which invitations would be handled. Parents involved.

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As presented in Table 26, all of the clients are in supported living arrangements and two (2) of the four (4) are working in the community. Additionally, there was evidence that all of the clients made decisions regarding the "who, what, where and when" in making arrangements for their person-centered planning meeting. There is also a sense of individuality present in the plans. Community desires and activities the person likes are specific (e.g., different activities between clients, not just that someone likes TV but rather they like particular TV shows).

Broad planning/implementation related documents yielded the strongest and most accurate description of both self-determination and community inclusion. However, the organization demonstrated limited efforts in monitoring/evaluation practices. At the same time, client plans reflected very strong application of the self-determination and community inclusion concepts.

Content Analysis Findings Summary

All of the organizations provided evidence that indicated the overall structure was supportive of and conducive to practices associated with self-determination and community inclusion. For example, organization vision, mission, and values statements reflected directions and expectations that spoke to such concepts as full

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citizenship, community-inclusive opportunities, and person-centered planning. Additionally, goals and objectives included activities such as the expansion of community-inclusive activities (e.g., supported living and employment opportunities). Self-determination was also evident in the specific efforts of the organization. There was evidence, with varying degrees, that the organization had created self-determination relevant policies, procedures, and practice guidelines (e.g., fiscal intermediary, self-determination protocols).

With the exception of Organization D, which was comparatively more limited in macro oversight efforts, there were some inconsistencies in the application of self-determination practices and the pursuit of community-inclusive outcomes. The identification of desires, dreams, and likes was relatively strong. However, there was evidence of traditional programmatic interventions, as mechanisms for pursuing client desires, as well as the lack of natural supports and real inclusive outcomes.

In responding to the research question "Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion?," the evidence suggests some inconsistencies between the planning/implementation conceptualization of values and expression of operational knowledge and the

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FOCUS GROUPS

The purpose of the focus groups was to allow the examination of the research inquiry regarding differences between the direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative management staff, non-management administrative staff) organizational members relative to both self-determination and community inclusion perspectives.

The four (4) principles of self-determination and the two (2) key components of community inclusion served as the framework for compiling and sorting information (briefly summarized as follows):

1. Self-determination: (1) personal life plan through the application of person-centered processes, (2) controlling resources, (3) support to achieve desires and goals, and (4) responsibility as a community contributor.

2. Community Inclusion: (1) relationships with ordinary people and natural places in the community; and (2) supports, accommodations, and models of practice intended on promoting inclusive outcomes.

Two (2) focus groups were convened at each of the four

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(4) organizations: one comprised of direct members of the organization and the other comprised of indirect members of the organization. Focus group participants responded to ten (10) questions, five (5) each related to self-determination and community inclusion. Responses were recorded on newsprint verbatim or as abbreviated summaries (checking with participants to ensure accuracy). The focus group facilitators conducted a debriefing following each site visit in order to indicate the process of organizing the responses into the framework.

In presenting the findings, the focus group questions have been aligned into the following three (3) categories:

1. Conceptualization: Questions requiring participants to develop a definition of the concepts, describe the essential elements (self-determination only), or identify the outcomes (community inclusion only).

2. Impediments: Questions requiring participants to describe ethical considerations and identify practice barriers.

3. Expectations: Question requiring participants to develop a set of opportunities.

The self-determination findings are presented first, followed by the community inclusion findings. The presentations are by organization and compare the two focus groups: the direct group and the indirect group. The tables

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presented in the text are annotated summaries derived from the summary tables (Appendix I).

Self-Determination

Each of the two (2) focus groups at each of the four (4) organizations were asked to respond to the following questions:

1. How do you define self-determination for people with developmental disabilities?

2. What are the essential elements of self-determination practices for people with developmental disabilities?

3. What are the key ethical challenges evident in the application of self-determination practices?

4. What are the key barriers to the application of self-determination practices?

5. What are the key opportunities in the application of self-determination practices?

The subsections that follow provide a summary of the self-determination related focus group information as compiled and summarized.

Organization A

As presented in Table 27, both groups spoke to the clients having choice and taking control over their lives

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and engaging in the community. The indirect group also identified the client, rather than the professional, as driving the decision-making process while the direct group described the reciprocal nature and individual responsibility of the client in becoming a member of the community. Both groups addressed finance considerations with the direct group identifying the movement of funds from programs to individuals and the indirect group stating the need for clients to control funds. Both groups also identified education/learning as important; however, the direct group focused on the clients' learning while the indirect group offered a broader definition of education (including client, parents, and others).

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Table 27

Organization A: Self-Determination Related Focus Group Summary

Direct	Indirect
Definition and Essential Elements	
Choice, control, direction over life; being part of community and control; being responsible; learn about options, opportunities, potential experiences; movement of funds from programs to individuals	Choice, power, and control; we used to decide, now they do; education (clients, parents, schools, community) and experience (client); control of funds (through budget support)
Ethics and Barriers	
Health/safety within context of laws; mediating guardians overstepping legal authority; families/guardians more restrictive due to historical message; adverse Medicaid policies and ability to move funds to individuals	Greater risks and rights and responsibilities; professionals work through issues with families/guardians; parents and guardians have difficult time letting go; resources (financial, poverty, Medicaid prohibitions); organization liability; community characteristics
Opportunities	
Having what one wants in life; building friendships, increased community connections; reduction of systems dependency and resulting ability for system to serve more people	Economic advances by the community by including people with disabilities; organization allowed to think out-of-the-box; less dependency on system will allow for increased number of people served

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Both groups identified health and safety concerns as ethical considerations. The direct group was concerned with the need to apply the standards of law and also the safety of others in regards to health and safety considerations while the indirect group was concerned with the increased risks and responsibilities assumed by clients. Guardian related issues were also addressed by both groups with focus on the need to work through differences between the guardians' desires (relative to scope of responsibilities) in conflict with the clients' desires, as well as restrictive problems resulting from the historical messages received by guardians (e.g., movement from institutions to institutional arrangements in the community to support-oriented alternatives in the community). Both groups described problems related to Medicaid that prevent clients from controlling funds. The direct group addressed problems in moving funds from programs to individual clients while the indirect group provided a broader description of resource limitations which included financial (e.g., poverty), human (e.g., organizational liability concerns such as co-employment), and community capacity (e.g., community housing).

The reduction of systems dependencies and the resulting available resources to support and serve additional people were identified by both groups as an opportunity inherent in

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self-determination. The direct group also focused on client outcomes related to building friendships and connections with the community and increased self-worth, while the indirect group focused more on the benefits to the community (e.g., economic benefits) and organization (e.g., allowance to "think-out-of-the-box").

Key self-determination discussions reflected a good amount of consistency (between groups) and accuracy (to the concept) in both groups. For example, both groups spoke in the same manner with regards to clients having choices and taking control over their lives, problems with guardians, historical influences, and reductions on systems dependencies. Both groups also spoke to clients making choices and taking control.

Organization B

As presented in Table 28, the indirect group was most focused on concepts related to the clients being given power, including over the financial resources included in support plans, making life decisions, and becoming more knowledgeable about resources, the community, and the potential implications of decision-making. The direct group spoke primarily to concerns of control and freedom in making life decisions and taking responsibility, support of client learning through new experiences, and development of a

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Table 2

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Table 28

Organization B: Self-Determination Related Focus Group Summary

Direct	Indirect
Definition and Essential Elements	
Being in control, freedom; becoming own person; allowed to make mistakes; making own decisions; developing natural circles of supports and gaining exposure and taking responsibility for self; teaching individuals what they can do working from their strengths	Giving control to person; opportunities to make informed decisions; inclusion of all financial resources as their personal budget; knowledge of resources (financial as well as human)
Ethics and Barriers	
Organization learning to let go; determining who is actually in control; resistance to change (communities, professionals, clients, families)	Influenced by others making decisions or imposing values; liability concerns of the organization; resistance to change (parents, professionals); dismantling old system
Opportunities	
More enriched and meaningful contact between clients and staff; client is better person to be around as they are getting what they want and feeling better about themselves	Clients become citizens; organization benefits as practices "bleed" to other people being served; diminished resource demands allows for more resources available

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The indirect group addressed three key internal organizational concerns: (a) liabilities, (b) provider and professional resistance to change, (c) and movement from financing of fixed-costs programs to individuals. Both groups were concerned with forces that may adversely influence client choices as well as resistance to change and historical influences.

As is evident, the direct group most identified the relationship between clients and professionals as a key opportunity resulting from self-determination practices. As clients acquire more of what they want in life and make more decisions in this regards, they become better persons to be around and are viewed and treated in more positive manners by supporting professionals. The indirect group focused on both the benefits to the organization (e.g., positive influence of self-determination practices on the broader organization, the freeing up of financial resources to serve additional clients) and the community (e.g., interpersonal and economic benefits associated with the expression of citizenship).

Discussions regarding self-determination found a good deal of consistency (between groups) and accuracy (to the concept) in both groups (e.g., client control, resistance to change, financing strategies). Additionally, and particularly relative to the opportunities of

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self-determination practices, the direct group was more focused on speaking to concerns that were more of a community and client nature while the indirect group was more focused on the internal, organizational considerations. Both groups also spoke of clients having the power to make decisions.

Organization C

As presented in Table 29, both groups reported that clients are engaged in a process that allows them to make choices regarding their lives (e.g., where to live, work) and pursue their dreams. With variation, both groups also spoke to the concept of the client making informed choices (the direct group stated "opportunity to understand how to make informed choices"; the indirect group stated "teaching how to make good choices"). The direct group described the alignment of a personal budget with the person-centered plan and client responsibility for resource management while the indirect group identified individualized budgets and the movement away from program directed financing and control.

Table 2

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Table 29

Organization C: Self-Determination Related Focus Group Summary

Direct	Indirect
Definition and Essential Elements	
PCP process client makes dreams and makes choices; personal budget aligned to the PCP; resource management responsibilities	Process of normalizing ones life through making choices; individualized budget (movement of program funds to individuals); offer choices and teaching how to make good choices
Ethics and Barriers	
Health and safety balance; myths held by the community (fear); lack of natural supports	Health and safety concerns in allowing a balance; public policy direction (as related to managed care) is short term sighted; community education so they will learn how to accept "those people"
Opportunities	
Changes occurring with individuals resulting from fulfilled dreams and lives; positive influences (guardians, community); movement away from "paternal government" lends to decreased costs	Reduction in costs to the system resulting from client decision-making; happiness, fulfillment, and quality of life; change in public perceptions resulting from clients inclusion in mainstream activities

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Both groups raised concerns with health and safety issues and the balancing of said concerns (e.g., client values versus individual and/or professional values/ethics, least restrictive pursuits, provider and professional incentives, vulnerability of clients). The direct group addressed community concerns (e.g., myths held by individual client supporters and general members of the community, capacity issues related to natural supports) while the indirect group was concerned about the educational needs of the community as well as the potential negative impact of contemporary public policy (e.g., managed care).

Both groups identified diminished costs as an opportunity of self-determination. Additionally, both groups addressed community and client-level positive outcomes resulting from the fulfillment of client dreams and increased positive perceptions as developed by other members of the community.

Discussions regarding self-determination found a good deal of consistency (between groups) and accuracy (to the concept) in both groups (e.g., client control and choice regarding their lives, balancing health and safety concerns against client values and desires, positive outcomes for both the client and the community). One area of divergence that is noteworthy involves the more distant macro-based concerns raised by the indirect group (e.g., public managed

care policy) in contrast to the more local macro-based concerns raised by the direct group (community) regarding barriers.

Organization D

As presented in Table 30, both groups described clients as having opportunities to live their lives, make decisions, and control their lives just like anyone else does. Both groups also identified people in the community as providing natural supports to the client. The direct groups addressed the person-centered process involved in pursuing client desires, looking at various ways to move clients toward where they want to be, and removing barriers. The indirect group addressed funds available to purchase supports and to allow clients to take part in activities.

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Table 30

Organization D: Self-Determination Related Focus Group Summary

Direct	Indirect
Definition and Essential Elements	
Life for clients should be no different than it is for anyone else; PCP(comprised of family, friends, community members) get-togethers to identify things to happen (things in their life); elimination of all barriers and notions of barriers	Clients get to make life decisions just like everyone else; funds to purchase supports and take part in activities; development of natural supports through community activities; natural supports helping clients achieve goals
Ethics and Barriers	
Limitations to "I get whatever I want"; disagreements with guardians and families; public opinion (ignorance, bias, fear, intolerance, stereotyping); inexperience and limited experience of clients	General vulnerability that comes with a lack of life experiences; strong personalities of a relative or support staff that could lend to supporting their own decision rather than the clients; community acceptance resulting from stigma
Opportunities	
Becoming a citizen versus a consumer; Becoming visible and spending time with people (non-paid) in the community	Living like the rest of us; learning from mistakes; teaching clients responsibilities

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As presented in Table 30, both groups described concerns with public opinion and community stigma. Also, both groups raised issues regarding health and safety as related to client decision-making, particularly as related to the limited life experiences of clients. The direct group identified issues related to the expenditure of resources (e.g., limits on people getting "whatever I want," use of public funds considerations) and disagreements with people who could be making choices for clients (e.g., family, guardians). The indirect group had a similar concern with support staff who may act in a manner that is self-serving rather than abiding by the decisions of clients.

Both groups described opportunities for clients to experience citizenship and freedoms just like "all of us." The indirect group identified additional opportunities to include teaching client responsibility and allowing clients to learn from mistakes. The direct group identified the opportunity for clients to become reciprocal and visible participants in the community.

Discussions regarding self-determination found a good deal of consistency (between groups) and accuracy (to the concept) in both groups (e.g., clients as controlling their lives just like anyone else, stigma issues, health and safety concerns).

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Community Inclusion

Each of the two (2) focus groups at each of the four (4) organizations were asked to respond to the following questions:

1. How do you define community inclusion for people with developmental disabilities?

2. What are some key community-inclusive outcomes?

3. What are the key ethical challenges evident in the pursuit of community-inclusive outcomes?

4. What are the key barriers in the pursuit of community-inclusive outcomes?

5. What are the key opportunities in pursuing community-inclusive outcomes?

The subsections that follow provide a summary of the community inclusion related focus group information as compiled and summarized.

Organization A

As presented in Table 31, the direct group described the concept of community inclusion primarily as clients having access to and becoming involved in community activities in the same manner as are available to anyone else. The indirect groups also addressed becoming involved in routine activities as well as having opportunities to meet other members of the community and develop

relationships. Both groups spoke to a positive effect on the community attitudes.

Table 31

Organization A: Community Inclusion Related Focus Group Summary

Direct	Indirect
Definition and Outcomes	
Engaged in activities available to everyone in the community; self worth and changing (to positive) social attitudes	Meeting others in the community; making new contacts; increased community support, acceptance and recognition
Ethics and Barriers	
Health and safety (safety of others); client related standards not other personal standards; boundaries in relationship between professionals and clients; resources; increased vulnerability	Blurring of boundaries (between client and professional); determining who is and who is not a good candidate for community inclusion (as related to vulnerability); resources; Medicaid finance policy limitations (home ownership)
Opportunities	
Increased independence, skill-building; improved self-esteem resulting from increased involvement with community	Educate community and change public perceptions; more collaborative efforts where everyone in community benefits

Both groups raised ethical concerns regarding issues pertaining to the relationship between professionals and clients. Health and safety considerations were raised by the direct groups (e.g., safety of others) and as related to the clients driven standards whereas the indirect groups spoke to safety considerations as related to the appropriateness of a client to be a candidate for community inclusion. Both groups were concerned with real or perceived vulnerability. Both groups also spoke to human and community resource limitations with the indirect group raising limitations imposed by Medicaid regulations relative to people owning homes.

The direct group expressed opportunities primarily in the interpersonal and personal aspects of the clients. The indirect group was more focused on community opportunities.

The direct and indirect groups both responded to each of the community inclusion focus group questions in a similar manner (within as well as between the groups). One point of divergence was the indirect group's interest in community opportunities in comparison to the direct group's interest in opportunities for internal and external client development. Additionally, the indirect group identified a regulatory barrier to pursuing housing alternatives for clients. Both groups also spoke with accuracy regarding the concept of community inclusion.

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Organization B

As presented in Table 32, both groups identified reciprocal relationships placing the client in a "give and take" role with the community as well as making connections with community members. The indirect group also identified the dismantling of the service delivery system as one of the essential elements of community inclusion. The direct group stated that the community offered a better place for clients to live and would benefit from the inclusion of people with disabilities.

Table 32

Organization B: Community Inclusion Related Focus Group

Summary

Direct	Indirect
Definition and Outcomes	
Reciprocal relationships (something expected of both parties); developing reciprocal relationships; community as a better place to live (diversity and acceptance leads to improvements)	Reciprocal role as the client is both giving and taking from/with the community; identification with the community as evidenced in developing relationships; dissolving service delivery system
Ethics and Barriers	
Maintaining segregated activities because choice is limited; inaccurate assumptions regarding natural supports; prejudices	Community safety issues (clients with history of behavior problems and public safety); increased vulnerability and greater exposure to community prejudices; economic issues (poverty and financial resources)
Opportunities	
Growth for all; increased client self-esteem	Able to serve more people due to reduced costs and increased savings

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The direct group was most concerned with segregation as a result of the limits placed on client choices due to resource issues, values imposition, and public safety concerns. Additionally, the direct group was concerned with inaccuracies relative to natural support capacity assumptions. Both groups identified prejudice as a concern. Similar to the direct group, the indirect group also raised issue with community safety concerns; however, emphasis was on the factors associated with integration, client vulnerability, and client poverty.

The indirect group was most interested in the economic related community inclusion opportunities (e.g., reduced costs would allow the organization to serve more people, expansion of employment opportunities). The direct group was most interested in the opportunity for client growth and increased self-esteem.

Both groups were similar in regards to the community inclusion items (within as well as between the groups). However, it is worthwhile to note that the one difference found was the indirect group's concern with economic related matters (e.g., client poverty, savings created) that were not evident in the responses of the direct group. Both groups also seemed to convey an accurate picture of the concept of community inclusion.

Organization C

Both groups spoke to the availability of transportation as a benefit for the entire community which should result from community inclusion efforts (Table 33). Both groups described the nature of inclusion in a different manner but were complimentary. The direct group spoke specifically to the concept of integration into the social fabric. The indirect group focused on independence and movement into non-segregated arrangements. Thus, the indirect group spoke to the process of movement into community-inclusive opportunities while the direct group spoke to movement while in community-inclusive arrangements.

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Table 33

Organization C: Community Inclusion Related Focus Group Summary

Direct	Indirect
Definition and Outcomes	
Integrated into social fabric (no more "us" and "them"); transportation available to all people; client and community benefit (filling employment needs)	Working and living independently; clients and community fulfilled through development of non-segregated arrangements, visibility, reciprocal relationships; transportation services across the community
Ethics and Barriers	
Accommodations in the community and public values and social norms; sexual relationships; resource limitations; control issues (providers not relinquishing control, historical message)	Need a balance between public/community perspective with a consideration to what are best described as biases and prejudices and individual abilities; resource limitations
Opportunities	
Benefit to community (overall increased housing); more well rounded life for the client (become involved in individually chosen activities rather than group activities)	Small town nature of community lends to clients "not getting lost"; higher visibility leads to increased acceptance

Both groups raised concerns related to relinquishing of controls to clients. Both groups also spoke to resource limitations, but only specifically shared concern regarding transportation. The direct group identified housing, support services, and public guardians as resource limitations while the indirect group identified employment, human services, and social opportunities. Ethics were presented differently by each group. The direct group raised concern with accommodating needs that may come into conflict with public norms as well as concerns of sexual relationships. The indirect group spoke about the need to create a balance between public safety concerns and the abilities of the client as well as managed care being a covert catalyst to community inclusion (as an effort to simply cut people off).

The two groups responded differently to the opportunities inquiry. The direct group identified key community-inclusive opportunities to be community benefit and a more rounded life for clients. The indirect group described opportunities derived from the "small town" nature of the community, how people look out and care for each other, as well as the relationship between increased visibility and acceptance.

Both groups seemed to accurately described community inclusion with some commonalities between the responses provided. As one point of departure, the direct group was

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more consistently focused on the community influence of inclusion (e.g., integration into social fabric, community benefits, conflicts with social norms) as compared to the indirect group.

Organization D

As presented in Table 34, both groups acknowledge clients as being like everyone else in the community (e.g., having opportunities, participation, accessibility, contributions) and the opportunity for greater public acceptance. Both groups also identified public education as a community-inclusive outcome. The direct group also spoke to the personal and interpersonal development of clients as a result of increased community experiences.

Table 34

Organization D: Community Inclusion Related Focus Group Summary

Direct	Indirect
Definition and Outcomes	
Clients as having the same opportunity as everyone else; be accepted as a person as opposed to a disability stereotype; life skills and growth resulting from experience, more appropriate behaviors and expanded friendships; giving back to the community and reduced ignorance, stereotypes	Participating in the community like everyone else; greater public acceptance; educating the public
Ethics and Barriers	
Greater potential for vulnerability and victimization; behaviors come into question (sexually inappropriate actions that could lead to arrest); poverty	Concern that client may work harder in the community and could be taken advantage of (illegally) by employers; stigma of disability; lack of community accessibility (ramps, elevators)
Opportunities	
Self-worth, positive self-image as well as increased community awareness and education leading to personal growth of community members; opportunity to move out of poverty	Economic advantages (more workers earning more money to be spent); community exposure as contributing to a greater public perception and appreciation of differences; client happiness and improved self-esteem

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Both groups identified client vulnerability as related to being taken advantage of (e.g., by employers, telemarketers, acquaintances) as an ethical dilemma in pursuing community-inclusive opportunities. The direct group identified poverty as a key barrier as well as behaviors (e.g., sexually inappropriate and illegal actions) as related to ethics. The indirect group was concerned with barriers resulting from a lack of accommodations to make the community accessible as well as the ethical concerns related to stereotypes and stigma.

Both groups identified improved sense of client self (e.g., esteem, worth, image) as being an opportunity resulting from community-inclusive efforts. Additionally, both groups spoke to the community gaining greater awareness and appreciation through a shared community. Indirect group identified the community economic benefit opportunity (e.g., workers earning and spending money) and direct group described community inclusion as providing an avenue out of poverty experienced by clients.

There was a good deal of commonality in the manner in which each group responded to the questions (e.g., clients like anyone else in the community, vulnerability concerns, sense of self). Both groups also spoke to poverty, with the indirect group moving beyond the individual benefit of moving out of poverty to include the community benefit. The

direct group may have been marginally more focused on the personal and interpersonal influences of community inclusion while both groups portrayed community inclusion in an accurate manner.

Focus Group Findings Summary

With only slight variations, the themes presented by the direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative management staff, non-management administrative staff) groups were consistent and accurate within and between the groups as related to both concepts (self-determination and community inclusion). Self-determination was described as clients making choices, having the power to make decisions, taking control over their lives and living in the community in the same manner as everyone else. Impediments included historical influences (particularly as it related to people wanting to control clients lives) and health and safety concerns.

There was also a good deal of consistency between the groups relative to the concept of community inclusion. However, there was a consistent pattern of slight divergence, although not detracting from accuracy, for each organization. For example, in two of the direct groups, the participants were more consistently focused on the personal

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and interpersonal developments of the clients (e.g., self-esteem, development of relationships) in comparison to the indirect groups.

In response to the research question regarding direct and indirect group differences and commonalities, there were only marginal differing perspectives between the two groups relative to both self-determination and community inclusion while both groups sufficiently articulated perspectives relative to both self-determination and community inclusion.

SELF-DETERMINATION AND COMMUNITY INCLUSION SCALE

The purpose of the survey scale was to allow a quantitative examination of the research inquiries regarding differences between both the direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative management staff, non-management administrative staff) and leadership (CEOs, Board Members, Program Managers, CFOs, administrative management staff) and line (client support coordinators, non-management administrative staff) organizational members relative to both self-determination and community inclusion perspectives.

As described in the Methods chapter, the survey administered to participants included a thirty-four (34) item scale covering the concepts of self-determination and

community inclusion. Following the data collection and initial analysis, the following data considerations and scale modifications were made:

1. Missing Data: Of the 1,802 possible data responses (53 participants x 34 items), there were 37 missing responses with no item missing more than three responses. These missing data were replaced by the mean value of a participant's entire series of responses.

2. Deleted Items: Items #1 and #11 were deleted due to substantively lower item correlation which lowered the alpha reliability of the scale and subscales one (1) and two (2).

3. Subscales: Initially, as described in the Methods chapter, there were a total of eight (8) subscales identified in the instrument. As a result of the elimination of items #1 and #11 and the examination of the manner in which the items clustered, it was decided to decrease the number of subscales to six (6). Although the number of subscales were reduced, the concepts of self-determination and community inclusion remained intact. Only two (2) of the subscales described in the Methods chapter were affected by these modifications while all others remained intact. The subscale "Role of Professional" contained only two (2) indicators and was related to the concept of self-determination and to planning, thus, these were included in the "Planning Meeting Organization" subscale. Initial

subscale "Plan Characteristics- Central Theme" only contained one (1) indicator, was related to the concept of self-determination and was related to planning, thus, this was included in the "Planning Meeting Characteristics: Self-Determination" subscale.

The consolidated subscales (as initially stated in Chapter 3) are identified and described as follows:

1. Subscale #1 (Planning Meeting Organization: Self-Determination): Practices requiring the client to determine when, where, how often, and who will attend their planning meetings as well as the roles of the participants (scale items 2, 3, 4, 5, 6, 7, 8, 9).

2. Subscale #2 (Planning Meeting Characteristics: Self-Determination): Practices as they speak to planning meetings being focused on and reflecting the desires, abilities, and rights of the client and with problem solving intended to resolve barriers to the pursuit of their desires (scale items 10, 12, 15, 17).

3. Subscale #3 (Planning Meeting Characteristics: Community Inclusion): Outcomes as they speak to consider accommodation and support needs for natural community participation, exploring alternative opportunities in response to potential life experience limitations, and reasonableness in addressing legitimate health and safety needs (scale items 13, 14, 16, 21).

4. Subscale #4 (Plan Characteristics: Community Inclusion): Outcomes as they speak to the plan addressing outcomes related to clients' quality of life and pursuit of reciprocal relationships with ordinary people and natural places in the community (scale items 18, 19, 20).

5. Subscale #5 (Resource Command: Self-Determination): Practices as they speak to clients' control over financial and human resources relative to the provision of supports and services (scale items 22, 23, 24, 25).

6. Subscale #6 (Outcomes: Community Inclusion): Outcomes as they speak to achievements and opportunities regarding community living, employment, and socialization (scale items 26, 27, 28, 29, 30, 31, 32, 33, 34).

Instrument Reliability

A reliability coefficients analysis of the scale was completed.

Table 35

Reliability Analysis: Scale Alpha, Central Tendency, and Dispersion

Alpha and Central Tendency					
Subscale	Alpha	Items	*M*	*Mdn*	mode
1	.8289	8	31.00	32	29
2	.8492	4	18.29	19	20
3	.7448	4	18.62	19	18
4	.7596	3	13.06	13	15
5	.8791	4	15.97	17	12
6	.9151	9	38.10	39	39
Total	.9446	32	135.05		

Dispersion				
		Range		Potential
Subscale	*SD*	Min	Max	Max
1	6.48	19	45	48
2	3.55	8	24	24
3	3.09	11	24	24
4	2.31	8	18	18
5	4.34	6	24	24
6	8.35	22	54	54
Total	22.35			

Note: Subscale 3 had multiple modes. The mode presented is the lowest.

As illustrated in Table 35, the lowest alpha level was .7448 (Subscale 3) while the highest was .9151 (Subscale 6) with the scale total at .9446. The alpha levels suggest that the instrument has demonstrated reasonably high reliability (internal consistency). It is also noted that as the number of items on a subscale increase, alpha reliability also increases. All of the alpha levels are well above the acceptable cut-off (.70) with as few as three (3) items on a subscale. This seems to suggest that these subscales are reliable measures. Differences found among groups using these measures can be attributed more confidently to actual differences instead of measurement error.

An examination of central tendency reveals minor variations in the shape of the distribution. Subscale 2 is slightly positively skewed and Subscale 3 is multi-modal; however, as demonstrated in the standard deviations and range values, the distribution would be described as relatively normal.

Table 36

Subscale Central Tendency and Variability

Subscale	Item *M*	Item Variance
1	3.87	1.44
2	4.57	1.15
3	4.66	1.05
4	4.35	0.88
5	3.99	1.61
6	4.23	1.45
Total	4.22	1.32

Table 36 offers the item means and variability for each subscale. As presented, Subscale 3 was rated the highest overall and Subscale 1 was the lowest. In terms of variance, Subscale 5 had the greatest average dispersion and Subscale 4 had the lowest.

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Table 37

Subscale Correlations

Subscales	1	2	3	4	5	6
1	1.000	.626	.525	.425	.329	.525
2	.626	1.000	.812	.543	.348	.630
3	.525	.812	1.000	.490	.312	.565
4	.425	.543	.490	1.000	.493	.628
5	.329	.348	.312	.493	1.000	.691
6	.525	.630	.565	.628	.691	1.000

An examination of the correlations between subscales (Table 37) reveals that all of the subscales are significantly correlated ($p < 0.05$, two-tailed test). Of the six (6) subscales, Subscale 5 has the smallest correlation coefficients in the template ranging from .312 to .691. The smaller correlation coefficients indicate that Subscale 5 is assessing a different construct while the remaining subscales may be in fact unidimensional.

Although Subscale 5 generally has the smallest correlation coefficients in the scale, Subscale 1 loads on Subscale 4 and Subscale 6 lower in comparison to all other relationships with Subscale 1, including that of Subscale 5. However, these correlation coefficients are high nonetheless (.425 and .525); therefore these are only slightly better in

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The correlation coefficients raise concerns regarding the subscales inability to distinguish between concepts. A sample size of only fifty-three (53) poses limitations on any statistical technique used in this analysis. A confirming Subscale Analysis of the theoretical constructs (subscales) was not performed due to the small sample size (a Subscale Analysis would require a sample size of at least 100). Although the scale reliability was determined by a small sample, the alpha for the total scale was very high and the number of items (32) for the total scale was quite adequate (Spector, 1992).

The scale used in this study was developed for a specific population and then used to assess the intended population. The scale appears to be quite appropriate for the intended population as demonstrated by the obtained high alpha reliability coefficient. This lends confidence to the decision to use the scale for examining differences among groups. However, the correlation coefficients, taken in consideration with other limitations of this research effort (e.g., sample size), require the scale and subscales to be best viewed as exploratory measures.

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Statistical Application

The Kruskal-Wallis H test was applied in the subscales' comparative analysis between the four (4) organizations, between the four (4) organizational quadrants (leadership/direct, line/direct, leadership/indirect, and line/indirect), and between each of the two (2) organizational quadrants (leadership and line and direct and indirect) in examining each of the subscales. Similar to the Mann-Whitney U test, the H test is best used when there is no natural ascending or descending order of the sample population and it is intended to detect distributional differences between the independent samples through a process of creating ordered ranks of the data values (Kanji, 1999; SPSS 10.0, 1999; Wonnacott and Wonnacott, 1984).

The statistical test applied was chosen as the most appropriate and powerful non-parametric statistical method to use with a small sample size. Findings are reported as two-tailed tests with statistical significance established at $p < 0.05$. A limitation of the applied test is that, although the samples are similar in shape and the statistic provides a test of values converted into a rank order, it does not consider the difference between each of the ordered values. It should also be noted that given the exploratory nature of this research endeavor and the limitations created

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by the non-experimental nature of the research and sampling designs and sample size, reporting findings as statistically-significant is severely limited. Although tests of statistical significance are applied, at a minimum these should be recognized as good impressions and, at best, as having some substantively accurate meaning.

Scale Findings

Table 38

Survey Subscale Means by Organization

		Subscale Means						
Org	N	Total	1	2	3	4	5	6
A	13	29.92	33.88	34.00	31.19	29.15	21.58	28.15
B	13	17.04	20.46	19.69	17.50	21.31	22.54	17.23
C	14	28.75	26.82	27.11	28.86	29.93	30.21	28.89
D	13	32.15	26.85	27.19	30.31	27.38	33.42	33.58
x^2		8.506	4.930	5.643	6.747	2.581	5.596	7.869
p		0.057	0.177	0.130	0.080	0.461	0.133	0.049

df = 3

Key: df = degrees of freedom

As evident in Table 38, there is a statistically-significant difference among the organizations on Subscale 6

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(χ^2 = 7.869, p = 0.049, df = 3). Subscale 6 is identified as the outcome dimension of community inclusion as it speaks to community living, employment, and socialization opportunities. Low scores for Subscale 6 indicate diminished perceptions regarding the organizations' practices in community inclusion outcomes associated with supported living, employment, and socialization. Means for Subscale 6 ranged from 17.23 (Organization B) to 33.58 (Organization D).

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Table 39

Survey Subscale Means by the Four Organizational Quadrants

Quad	N	Total Means	Subscale Means 1	2	3
Le/D	12	27.17	28.63	23.17	28.50
Le/I	8	24.56	24.44	25.38	25.81
Li/D	21	26.88	24.48	29.43	22.98
Li/I	12	28.67	31.50	27.67	33.37
χ^2		0.343	1.953	1.384	3.606
p		0.952	0.582	0.709	0.307

df = 3

Quad	Subscale Means 4	5	6
Le/D	26.21	25.29	29.67
Le/I	29.75	28.63	26.69
Li/D	25.57	20.33	23.36
Li/I	28.46	39.29	36.17
χ^2	0.503	11.861	8.502
p	0.900	0.008	0.037

df = 3

Key: Le/D = Leadership/Direct, Le/I = Leadership/Indirect, Li/D = Line/Direct, Li/I = Line/Indirect, df = degrees of freedom

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As illustrated in Table 39, a comparison each of the four (4) organizational quadrants (leadership/direct, leadership/indirect, line/direct, and line/indirect), found statistical significance for Subscale 5 (χ^2 = 11.861, p = 0.008, df = 3) and Subscale 6 (χ^2 = 8.502, p = 0.037, df = 3).

Subscale 5 is identified as the resource command dimension of self-determination as it speaks to the client having control over both the financial and human resources involved in the provisions of supports and services. Low scores for Subscale 5 indicate diminished perceptions regarding the organizations' client command of resource practices. Means for Subscale 5 ranged from 20.33 (Line/Direct) to 39.29 (Line/Indirect).

Low scores for Subscale 6 indicate diminished perceptions regarding the organizations' practices in community inclusion outcomes associated with supported living, employment, and socialization. Means for Subscale 6 ranged from 23.36 (Line/Direct) to 36.17 (Line/Indirect).

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Table 40

Survey Subscale Means by the Four Organizational Quadrants: Rank Order (High to Low)

		Subscale Means Rank Ordered						
Quad	N	Total	1	2	3	4	5	6	χ^2
Le/D	12	2	2	4	2	3	3	2	2.67
Le/I	8	3	4	3	3	1	2	3	2.67
Li/D	21	4	3	1	4	4	4	4	3.33
Li/I	12	1	1	2	1	2	1	1	1.33

Key: Le/D = Leadership/Direct, Le/I = Leadership/Indirect, Li/D = Line/Direct, Li/I = Line/Indirect

Table 40 provides an illustration of the subscale means rank ordered by the four (4) organizational quadrants. As presented, the line/direct participants rated Subscales 3, 4, 5 and 6 the lowest of the four groups. These subscales are related to:

1. Community-inclusive planning related efforts of considering support and accommodation necessary for making natural community connections, exploring alternative opportunities, responding to legitimate health and safety concerns (Subscale 3).

2. Community-inclusive plan characteristics as related to outcomes contributing to improved quality of life and the

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pursuit of reciprocal relationships in the natural community (Subscale 4).

3. Self-determination related client control over both the financial and human resources involved in the provisions of supports and services (Subscale 5).

4. Community-inclusive outcomes community living, employment and socialization opportunities (Subscale 6).

Subscale 2 is related to self-determination planning meeting characteristics and centers on meetings focusing and reflecting client desires, abilities, and rights and removal of barriers through problem-solving. The leadership/direct participants reported the lowest perception of these meeting characteristics occurring while the line/direct participants reported the highest.

The mean presented at the far right of Table 40 represents the average rank for the six (6) subscales. As evident, the two (2) leadership quadrants rank average for the six subscales were the same ($\underline{M}$ = 2.67) while the line/direct had the lowest overall average ranking ($\underline{M}$ = 1.33) and the line/indirect had the highest ($\underline{M}$ = 3.33).

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Table 41

Survey Subscale Means by Organizational Horizontal Quadrants

			Subscale Means		
Quad	N	Total	1	2	3
Lead	20	27.42	26.13	26.95	24.05
Line	33	26.74	27.53	27.03	28.79
χ^2		0.024	0.103	0.000	1.184
p		0.876	0.748	0.985	0.276
df = 1					

	Subscale Means		
Quad	4	5	6
Lead	27.63	26.63	28.48
Line	26.62	27.23	26.11
χ^2	0.054	0.019	0.294
p	0.817	0.890	0.588
df = 1			

Key: Lead = Leadership

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Table 42

Survey Subscale Means by Organizational Vertical Quadrants

			Subscale Means		
Quad	N	Total	1	2	3
Dir	33	24.98	26.98	25.98	27.15
In	20	30.33	27.02	28.67	26.75
χ^2		1.490	0.000	0.382	0.009
p		0.222	0.993	0.537	0.927
df = 1					

	Subscale Means		
Quad	4	5	6
Dir	25.80	22.14	23.74
In	28.98	35.03	32.28
χ^2	0.536	8.755	3.904
p	0.464	0.003	0.048
df = 1			

Key: Dir = Direct, In = Indirect

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As evident in Tables 41 and 42, there is no reported statistical significance across any of the subscales as related to the horizontal organization. However, an examination of the vertical organization reveals statistically-significant differences for Subscale 5 (χ^2 = 8.755, p = 0.003, df = 1) and Subscale 6 (χ^2 = 3.904, p = 0.048, df = 1). There is a statistically-significant difference between direct and indirect participants perceptions of both the self-determination related resource command and the community-inclusive related outcomes subscales.

Summary of Scale Findings

An examination of the scale reliability rendered an overall alpha rating which indicates relatively high reliability. However, the correlation coefficients suggest that the subscales were unable to demonstrate distinctions between concepts. Additionally, research design considerations (e.g., sample size) suggest statistical findings be treated as exploratory.

Statistical significance was found for Subscale 6 (community inclusion- outcomes) among the organizations as well as the four organizational quadrants and also between direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative

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management staff, non-management administrative staff) participants. Statistical significance was also found for Subscale 5 (self-determination- resource command) between the four organizational quadrants and between direct and indirect participants.

Therefore, evidence is offered to support that there are some statistically-significant differences between the direct and indirect organizational members. Additionally, there are substantive differences between line/direct (client support coordinators) and the other three (3) organizational quadrants. Line/direct staff reported an overall lower perception of the manner in which the organizations' currently operate in applying self-determination practices and pursuing community-inclusive outcomes.

CHAPTER 5: ANALYSIS

This chapter first offers an overview of the key limitations of this research effort. This is followed by an analysis of the findings in relationship to the research questions. The third component examines the relationship between the findings and the review of literature contained in Chapter 1. The chapter concludes with a relevant examination of institutional and organizational arrangements.

Limitations

Related to the content analysis, organizations were provided a list describing documents they were to provide. This was communicated to them by letter as well as by phone. Additionally, two (2) organizations were contacted following the receipt of the source documents to request additional monitoring and evaluation-related source documents and, for one (1) of the organizations, policy-related resources. These source documents were requested because they were obviously lacking in the organizations' initial submission of the materials.

Although the parameters of what was needed was relatively prescriptive, there was some interpretive freedom. It is unlikely, but possible, that additional

critical documents were omitted from the organizations' submissions. This would include source documents reflecting favorably as well as unfavorably on the organizations. It would be reasonable to propose that, given the fact that the organizations were free to select the documents they were going to submit (including client plans, per consents being secured), there would be an incentive to submit documents that projected a more favorable image of the organization.

Focus group discussions were not audio or video recorded. Therefore, some information, including all tones and visuals, were not captured. Also, the groups were combined to include supervisory and subordinate members of the organization. It is reasonable to propose that the subordinate participants may have refrained from speaking critically in front of the supervisory staff. As a check in this regard, the individual survey completed by each participant included open-ended items mirroring the focus group questions. The researcher was then able to review the surveys in comparison to the focus groups to determine if there was any meaningful or substantial difference (of which there was none).

Although the survey instrument demonstrated reliability, there needs to be caution in the interpretation of "statistical significance." The exploratory nature of this research and the manner in which participants were

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selected as well as the limited number of participants involved raise issue with even the use of a non-parametric statistical test. Additionally, the ordered sequence of the indicators could lead to the participants identifying a pattern and discovering a subscale.

An examination of the correlations between subscales revealed that all of the subscales were significantly inter-correlated. Of the six (6) subscales, only one (1) had a relatively small correlation coefficient. The correlation coefficients raised concerns regarding the ability of the subscales to distinguish between concepts. The small sample size poses limitations on any statistical technique used in this analysis. Although the scale reliability was determined by a small sample, the alpha for the total scale was very high, and the number of items for the total scale was adequate.

The scale used in this study was developed for a specific population and then used to assess the intended population. The scale appeared to be quite appropriate for the intended population as demonstrated by the obtained high alpha-reliability coefficient. This lends confidence to the decision to use the scale for examining differences among groups. However, the correlation coefficients, taken in consideration with other limitations of this research effort (e.g., sample size), require the scale and subscales best be

viewed as exploratory measures.

The research conditions supported the statistical test applied (Kruskal-Wallis) as the most appropriate and powerful non-parametric method. However, it should be noted that given the exploratory nature of this research endeavor and the limitations created by the non-experimental nature of the research and sampling designs and sample size, reporting findings as statistically-significant is severely limited. Although tests of statistical significance were applied, at minimum these should be recognized as good impressions and, at best, as having some substantive, accurate meaning.

Summary and Discussion of Findings

The subsections that follow offer a summary of the findings presented by participant characteristics and by each of the three (3) research questions.

Participant Characteristics

Three of the four organizations are public community mental health systems involved in providing and/or contracting for a full range of specialty supports and services for people labeled mentally ill and children with severe emotional disturbances as well as people with developmental disabilities. Thus, as related to

self-determination and community inclusion, specifically for people with developmental disabilities, there may be inconsistencies in values and models of practice directed at the non-developmentally disabled populations. The fourth organization, a nonprofit agency, only provides and/or contracts specialty supports and services for people with developmental disabilities. However, in all four organizations, there are a limited number of clients in the RWJ-sponsored self-determination initiative. Therefore, even within the population of developmental disabilities, there may be conflicting values and models of practice relative to the manner in which supports and services are designed and carried out.

The three (3) public organizations were of comparable size and of similar rural-fringe type characteristics. The non-public entity was substantially larger and in an urban setting. Although differences between these organizations would be expected, it is also reasonable to propose that the scope of this research endeavor was such that said differences would be minimized. The focus of this research effort was on the RWJ component of the organizations, all of which were similar in duration of existence and size. Therefore, the organizations were examined both separately and collectively.

There is no reason to suspect that organizational

member participants could be categorized as different from what would be typically found in an organization providing supports and services to people with disabilities. Most of the participants were females, while males filled a proportionally greater number of leadership roles. With the exception of the urban site, all of the participants were white, and most were middle aged. Almost all of the participants were college-educated and, as would be reasonable to expect, individuals in leadership positions were more likely to have been employed in their current position, with the organization, and working with people with developmental disabilities longer than individuals in non-leadership roles. There was also a large number of persons who reported close personal proximity to people with disabilities (e.g., family members with disabilities, participants themselves diagnosed with at least one disability).

Although there were variations in the types of mental retardation (e.g., profound, severe, moderate, mild) and there was some evidence of secondary disabilities (e.g., seizure disorders, autism), all of the client plans reviewed reflected a primary diagnosis of mental retardation in these individuals.

Research Question #1

The first research question is stated as follows: Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion?

The content analysis provides the primary evidence to respond to this question. Overall, the organizations formally described and defined both concepts with relative accuracy in the planning and implementation source documents. "Accuracy" is defined as the consistency of the information contained in the source documents in relationship to the principles and practices of self-determination and community inclusion. This included relevant values as stated in statements of vision, mission, and values; relevant knowledge as described in organizational plans and goals and objectives; and relevant practice guidelines as presented in policies, procedures, and protocols.

The monitoring and evaluation source documents were not as accurate and somewhat inconsistent with regard to the concepts as compared to the planning and implementation sources. However, the greatest departure was evident in the client support plans which are application or practice source documents. A large number of client support plans in three (3) of the four (4) organizations showed evidence that

suggested the actual practice began to move away from the concepts at the intervention point. That is, a number of plans were accurately designed through the implementation component. At that point, interventions began to reflect more of a traditional approach of applying developmental and/or non-inclusive program strategies. Additional issues, such as the lack of natural supports involved (in planning as well as in the client lives) as well as occasional questions related to the planning meeting decision process (e.g., was the client actually in control) were evident.

Also, as related to the client plans, and to a lesser extent the monitoring and evaluation source documents, a lack of community-inclusive outcomes (e.g., social connections, natural supports, supported living, and employment) were evident. As related to resource command, in almost all cases where a individual budget was present, there was no evidence suggesting that the client had or did not have control of the resources nor was the concept of "control" defined. Also, there was only minimal planning and implementation source documents that spoke directly to the concept of resource control with the exception of articulating a value that this should be occurring rather than providing operational directions.

"Source documents" were considered the critical information source for providing a description of the

organizations' formal systems of direction and operation. The focus groups would be considered a secondary source of information. Focus groups lack the static record and "rule" nature of the source documents. However, the groups represent the organizations' verbally-communicated perceptions. In the same manner as the planning- and implementation-related source documents, the focus groups add further reinforcement to the relative strength of the organizations' ability to conceptualize the values, knowledge, and practice of the concepts. The focus group findings revealed that there is a relatively sound understanding of the concepts.

Research Question #2

The second research question is stated as follows: Between the direct and indirect organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concept of self-determination and community inclusion?

There were two key data and information sources that provide a response to this question--the survey scale and the focus groups. In the survey findings comparing the direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative

management staff, non-management administrative staff) participants, there was a statistically-significant difference found in two subscales.

Statistical significance was found between the groups on the self-determination related resource command subscale. This subscale contained four (4) indicators regarding the clients' control over financial and human resources involved in the provision of supports and services. In reference to this subscale, the indirect participants reported, on average, a more positive perception that the organizations were currently operating in comparison to the perceptions of the direct participants.

The second subscale that rendered a statistically-significant difference between the two groups was the community inclusion related outcome subscale. This subscale contained nine (9) indicators regarding the community living, employment, and socialization outcomes. In reference to this subscale, the indirect participants reported, on average, a more positive perception as to how the organizations were currently operating in comparison to the perceptions of the direct participants.

Both of these subscales are key components of the concepts. Controlling resources, particularly funds intended for the purchase of supports and services and the people who are providing them, is one of the four principles of self-

determination. This may in fact be the most powerful subscale as it moves purchasing power from the organization to the client. Supported opportunities in the community as well as socialization (as it contributes to the development of a natural support network) are the critical outcomes of community inclusion. Thus, there is a difference in the perceptions of the organizations between direct and indirect workers with regards to two pivotal practice aspects of the concepts being investigated.

The focus groups found little difference between the direct and indirect participants. Furthermore, there was a good deal of accuracy in the manner in which the concepts were developed by both groups. Resource-related concerns as well as inclusive-outcomes were raised by the groups as related to barriers present. Thus, there is an impression that the direct and indirect participants share concerns in this area.

The consistent and accurate (relevant concept-related information) manner in which the direct (CEOs, Board Members, Program Managers, client support coordinators) and indirect (CFOs, administrative management staff, non-management administrative staff) participants discussed the concepts of self-determination and community inclusion in the focus groups is a key finding. The organizational members clearly understood as well as bought into the concepts and "spoke the

same language." This is particularly critical as related to administrative managers and support staff. These individuals serve essential roles in supporting the organization's pursuit of its purpose.

There are two reasons why this is a very powerful finding. First, the RWJ-related efforts to systematically ensure that organizational members are adequately trained in the concepts is seemingly paying off. The self-determination initiative requires a radical departure from traditional practices of providing or arranging for services for people with developmental disabilities. These organizational changes require a harmonious commitment, understanding, and practice between the persons implementing supports and services and those persons responsible for providing administrative support. Second, as was presented in the findings relative to Research Question #1, although these organizations may articulate relevant values and knowledge well, there is some difficulty with the actual practice of the concepts. This seems to raise a question regarding the level of energy that it would take to move a traditional organization into exemplar practice. That is, if these are the "best of the best," how could other agencies, without the advantage of the RWJ-related support, possibly achieve the level of inner organizational change and continuity necessary for self-determination and community inclusion?

There are several key characteristics that may serve to mitigate problems potentially encountered by other organizations pursuing these practices without RWJ support. For example, organizations that have a strong commitment to adequately training staff in new models of practice would be more likely to seek out support for learning that may not occur in an organization that does not have a strong value for developing new and relevant competencies. Also, an organization with a culture that desires to promote continuity in communication, planning, effort, and understanding between and across its structure would be better served in achieving the cross-organizational cooperation needed to best pursue the practices of self-determination and community inclusion as compared to organizations that operate in a severely segregated and fragmented manner.

Research Question #3

The third research question is stated as follows: Between leadership and line organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concepts of self-determination and community inclusion?

The survey scale was the primary data source providing a response to this inquiry. In the survey findings comparing

the leadership and line participants, there was a statistically-significant difference in one subscale, Subscale 6 (community inclusion- outcome). On this subscale, leadership participants (CEOs, Board Members, Program Managers, CFOs, administrative management staff) reported, on average, a more positive perception of how the organizations were currently operating in comparison to the perceptions of the line participants (client support coordinators, non-management administrative staff).

The line/direct participants (client support coordinators) reported more negative perceptions regarding client-level planning reflecting considerations of support and accommodation intended to promote natural connections, outcomes of improved quality of life, control over financial resources, and inclusive opportunities as compared to all other organizational quadrants (line/indirect, leadership/direct, leadership/indirect).

The content analysis findings lend support to the findings presented in the preceding paragraph. As was stated in response to the first research question, the accuracy (as related to the concepts) diminished as the focus moved from conceptualization to ultimate application. These findings may suggest that the leadership staff, focused on the conceptualization of the concepts, may have a more positive outlook on the manner in which they are being pursued as

compared to the line staff with their practice focus.

Relevance to Literature Review

A number of barriers to self-determination practices and community inclusion identified by the research participants parallel the literature. Community issues included acceptance of people with disabilities into the community, particularly as related to social values, as well as negative perceptions and stigma (Galloway, 1980; Asch, 1986; O'Connell, 1988; Shadish, Lurigio, and Lewis, 1989; Arens, 1993). Stakeholder issues included guardians acting beyond their scope of authority, variations among the values of professionals and clients, professionals giving up control to clients, ambivalence of families as related to divergence from past practices, clients' lack of life experiences and conflicts with the values of the organization itself (Siporin, 1982; Sherman and Cocozza, 1984; Ursprung, 1984; O'Connell, 1988; Woody, 1990; Dean and Rhodes, 1992; Rhodes, 1992; Amando, Conklin, and Wells, 1990; Walden, Wolock; and Demore, 1990; Fleck-Henderson, 1991; Stebnicki, 1994; Abramson, 1996; Hagner, Helm, and Butterworth, 1996; Wolf-Branigin, 1997; Reamer, 1998).

The clients' development of a life plan, control of resources, provision of support to obtain goals, and assumption of responsibility for contributing to the

community are the four principles of self-determination (Nerney, 1998). Person-centered planning is the method in which self-determination is operationalized. The core values of person-centered planning find the client driving the process; include supportive people who have a relationship with the client; involve the transference of power from "helpers" to "helped"; are action oriented, focused on positives (e.g., attributes not deficits), and dynamic; and, allow for multiple perspectives in order to expand creative problem solving (Allen, 1993; Marrone, Hoff, and Helm, 1997). Central to self-determination practices and person-centered processes are the concepts of client control, choice, decision-making authority, and overall empowerment, influenced by internal and external forces to the client's circle of support (Hoffman and Field, 1995; Hagner, Helm, and Butterworth, 1996; Ofiesh and Boone, 1996).

The findings of this research effort suggest that there is agreement among and within the organizations regarding the conceptual values and practices of self-determination, including person-centered planning. Furthermore, in the manner in which these concepts were expressed, it is reasonable to suspect that there is a sound level of relevant conceptual knowledge. However, there was evidence that the application of micro practices, at client-level intervention points, began to move away from the manner in

which the concepts should be operationalized.

Even if self-determination practices occur in an appropriate manner, if there is no real pursuit of community inclusion clients will not realize the ultimate goal of full citizenship (McGrath and Grant, 1992; Hoyle and Kloc, 1995). Community inclusion is defined as a set of reciprocal relationships with ordinary people and natural places in the community, together with supports and accommodations as augmentation to natural supports (O'Connell, 1988; Mount and Zwernik, 1989; Allen, 1993; Ferguson, 1993; Pearpoint, 1993; Mount and Zwernik, 1994; McNulty, Connolly, and Wilson, 1996; O'Brian and O'Brian, 1996). Increases in reciprocal, natural community relationships form the essence of the practice of community inclusion (Hagner and Dileo, 1993; Butterworth, Hagner, Kiernan, and Schalock, 1996). Consistent with the literature, the findings reported here suggested that fundamental community inclusion values as well as the knowledge of the concept were present. However, pursuit of community-inclusive opportunities--the practice of the concept itself--is where problems, both perceptual and in actual application, were most evident.

One of the key implications of community inclusion evident in the literature was the need for organizations to move toward financing support for clients (support models) as opposed to funding structured programs (Mount, 1990;

O'Brian and Lovett, 1992; Wolfe, Ofiesh, and Boone, 1996; Henery, Keys, and Balcazar, 1996; Harper, 1996; Smull, 1998; Mount and Zwernik, 1989). Consistent with the literature, subjects raised the financing-related concern of the movement of resources from programs to people as well as the ultimate economic concern--poverty and disabilities (O'Brian, 1991; Rimmerman, Botuck, and Levy, 1996; Nerney, 1998).

The practice of self-determination includes requirements that clients control a set amount of resources as a mechanism of controlling support purchase decisions (O'Brian, 1991; Nerney, 1998). This is intended to get at both the movement of finances from programs to people concern as well as serving as a mechanism to mitigate poverty. The research effort revealed that, in some instances, there were fiscal intermediary policies and individual budgets present. At the same time, line staff (client support coordinators, non-management administrative staff) serving in direct service roles reported lower perceptions of clients controlling financial resources as compared to leadership staff (CEOs, Board Members, Program Managers, CFOs, administrative management staff). This raises a level of doubt concerning the organizations' commitment to clients controlling financial resources for purchasing supports and services.

In terms of "big picture" economic concerns, there was virtually universal agreement among the participants that self-determination and community-inclusive efforts would result in reductions in overall costs to the organization. This was identified as related to clients increasing connections to natural supports which, in turn, would lead to diminished needs for specialty supports and accommodations. The literature warned that, although cost reductions may result as a residual effect, the sole purpose of natural supports are not intended to replace needed supports and reduce organizational costs (Rogan, 1996; Trach and Mayhall, 1997).

Content source document information collected suggested that connections to natural supports are somewhat breaking down in client-level practice. At the same time, line/direct organizational members (client support coordinators) reported more negative perceptions of the organizations' practice of clients making inclusive connections as compared to leadership staff. This again raises questions regarding the organizations' support of a critical component of the concepts--community-inclusive connections to natural supports. It is also noted; however, in terms of overall organizational practice, there was evidence that reflected movement away from financing programs (e.g., reducing capacity of day programs; expanding supported living

opportunities).

The three methods (content analysis, focus groups and individual surveys) applied in this research endeavor were intended to cover the breadth and depth of the organizations' efforts in stating values, exhibiting knowledge, and engaging in practices of self-determination and pursuit of community-inclusive outcomes. In a study by McNulty, Connoly, and Wilson, 1996, the researchers stated that organizational leaders needed to establish self-determination and community inclusion values, making them clear, understandable and sufficiently-explicit to all stakeholders. The study concluded the better the leadership accomplished these ends, the greater the likelihood was of acceptance and commitment to the values. A second conclusion was that to create change, organizational leaders needed to be value-oriented, to allocate organizational resources in a manner that supported the related practices (in this example, person-centered planning practices), and to expect people with disabilities to drive the process.

As was evidenced in the subscales related to resource control and connections with the natural community, there were mixed findings in the study at hand. In comparison to leadership staff, line staff perceived the efforts of the organization more negatively in critical areas of community inclusion (e.g., supported employment and living, forming

reciprocal relationships with ordinary people in the community) and self-determination (e.g., client control of resources). At the same time, leadership staff perceived the manner in which planning meetings reflected the desires, abilities and rights of clients more negatively as compared to line staff. These findings were related to practice concerns and seemed to reflect "pointing blame" at each other for responsibilities (leadership as policy formulators and "barrier busters," and line staff as policy-implementers). However, as related to values and knowledge-related considerations, evidence suggested much more consistent messages between leadership and line staff and in the manner in which the organization formally portrayed the concepts.

The participant organizations of the research effort described in this dissertation were all RWJ self-determination sites. Thus, the assumption at the onset was that all of the organizations had established relevant values, knowledge and practices. There was evidence that organizational members, particularly line/direct staff, had training in the areas of self-determination, person-centered planning, and community inclusion. Training in these concepts is critical. In a prior study involving community support workers, the researchers found training in community inclusion philosophy increased positive attitudes, job

satisfaction, and knowledge and increased self-report of organizational adherence to inclusive practices (Henry, Keys, and Balcazar, 1996). The researchers also found that direct support staff attitude and commitment were not as strong as that of persons in leadership positions.

The current study suggests that the organizational members are aware of critical community and stakeholder barriers to self-determination and community inclusion. Furthermore, the findings suggest that the organizations have keen and accurate conceptual understanding of relevant values, knowledge and practice. However, it is in the actual application of the concepts where there is a "drift" and misdirection. Additionally, there is variation in the perceptions of organizational members as related to the manner in which the systems demonstrate their commitment to these concepts. This variation was most evident between the "direct" leadership and line participants.

The findings of this research effort also reflect that the organizational members are aware of the need to move from financing programs to re-directing resources into the control of clients for making support purchasing decisions, as well as the impediments resulting from the pervasive problem of poverty. There was also acknowledgement that natural support connections would diminish costs. There was evidence of organizational efforts to promote natural

connections and support models of practice, and evidence that indicated efforts were being pursued at a client-level. However, findings did not support this occurring systematically and in all instances nor was there concurrence that it was perceived as happening as it should.

The correlation coefficients of the closed-ended component of the survey instrument revealed that the scale, with the exception of the resource control subscale, was unidimensional. As was evident in the literature, and consistent with the findings of the content analysis and focus group in this study, in some areas, the conceptual definitions of self-determination and community inclusion seemed to reveal overlapping and blurred boundaries between the two concepts (e.g., relationships with people, citizenship responsibilities, support and accommodation). The unidimensional nature of the survey instrument used in this research effort as well as the findings of the study (as supported by the literature) suggests the emergence of a model that brings the two concepts together. Arguably, self-determination and community inclusion find similar roots in concepts such as normalization and disability rights. Furthermore, both concepts ultimately seek to find people with disabilities enjoying greater freedoms in the community through a process of developing relationships and being supported and accommodated in a manner that allows the

fullest achievement of life's desires. Thus, the emergence of these two concepts as a single conceptual model seems logical. This is clearly an area calling for further research.

Systems: Arrangements and Organizations

Two key findings of the current study involved concerns related to clients controlling resources and opportunities and achievements of community-inclusive outcomes. These are considered important findings as they relate to critical elements of both self-determination and community inclusion (e.g., individual budgets; supportive models of practice). Most importantly, the client as purchaser and the client assuming full citizenship are necessary, as well as linked practices if self-determination and community inclusion are to be realized.

The focus of this component of the analysis is two-fold. First, there is an examination of market and non-market systems and institutional arrangements related to self-determination practices and the pursuit of community-inclusive opportunities and outcomes. Traditional practices find people with mental retardation (clients) captive to the purchasing decisions made primarily within non-market systems (where public entities and nonprofit organizations have implementation responsibilities) applying institutional

arrangements that exclude clients from purchase decisions.

The second area involves an examination within the organizations themselves. Self-determination and community inclusion are defined as policy innovations and pose challenges to organizations to move away from professionally-driven, traditionally service-delivery approaches to placing the client in command of processes and outcomes and ensuring support to meet these desires. This requires consistency in communication, commitment and understanding between the leadership and line staff within an organization. The findings in this research revealed differing perceptions regarding the manner in which the organizations were operating relative to the practices of self-determination and the pursuit of community-inclusive opportunities and outcomes.

Institutional Arrangements and Markets

The two concepts involved in this study could be described as contributing to ultimate privatization--intended beneficiaries making purchasing decisions within a market structure. In this role, government intervention intended to correct for market imperfection is primarily achieved through a form of individual subsidy. The imperfection being corrected would be defined as a response to poverty (distributional inequity) which limits the scale

and scope of an individual's ability to engage in buy-sell transactions.

Supports and services for people with mental retardation is primarily a function of public policy managed and implemented by non-market systems--public entities and nonprofit organizations. Macro-level purchasers are defined as federal and state public entities, while micro-level purchasers are public entities and, potentially, with some limitation in responsibility and scope, nonprofit organizations. Traditional practices find the buy-sell arrangements held between local public entities and nonprofit organizations.

Typically, public entities serve as purchasers, and nonprofit organizations serve as sellers. Along with these systems controlling the buy-sell arena, assignment of responsibility to nonprofit organizations also creates distance from the macro public purchasers, particularly legislative bodies acting as policy monitors (Niskanen, 1975; Nakamura, 1980). At the same time, public entities taking on comprehensive and/or varied and multiple management and provider roles may result in policy implementation shortcomings (Okun, 1975; Schultz, 1977; Castellani, 1992).

Public entities encounter non-market failure: problems related to budget growth as an outcome, redundancy and

rising costs left unchecked through demand mechanisms, and excessive transfer related residual benefits assumed by the organization as opposed to the intended beneficiary (Musgrave, 1959; Wolf, 1983). Nonprofit organizations, with no mechanism to produce profit outcomes and as extensions of the public system (e.g., assigned implementation responsibilities through contractual agreements), are also subject to non-market failure. The exclusion of the client from these buy-sell arrangements prevents the ultimate beneficiary from exercising voice and exit options as expressed through purchasing decisions (Williamson, 1964; Hirschman, 1970). The restrictions of entrance into the buy-sell arena is evident in the institutional arrangements themselves. These systems take the form of arrangements that reflect public entities interfacing with other public entities, assuming sole responsibility, and/or including limited (in terms of numbers and responsibilities) nonprofit organizations (Savas, 1982; Savas, 1987).

The implementation of self-determination practices and pursuit of community-inclusive outcomes results in the need to look at modifying and changing institutional arrangements involved in the delivery of a public good. Traditional practices find supporting organizations typically being non-market arrangements: public entities and nonprofit agencies. In those instances where the non-market actor serves as both

the manager and provider, purchase decisions are controlled by the seller. In those instances the managing entity purchases supports and services from other non-market systems, and the buy-sell arrangements are between the two systems. Thus, traditional practices find purchasing controlled by stakeholder beneficiaries other than the ultimate, intended beneficiary--the client.

Traditional practice presents opportunities for non-market failure. First, there is a natural lack of competition in a non-competitive system of arrangements along with the lack of a supply-and-demand function that is inherent in a market system. This is further hampered by practices that are primarily concerned with process rather than outcome measures (e.g., the number of case management contacts as opposed to becoming gainfully employed). This lack of competition, along with the elusiveness of the purchase resulting from a process focus, creates incentives for budget-maximization as the ultimate measurable outcome. This may be mitigated, to some degree, through capitated financial arrangements. Unlike fee-for-service financing structures, the acquisition of capitated funds is not based on the delivery of processes (e.g., units of services) but rather on performance-based outcomes (e.g., client satisfaction, improved quality of life).

With no demand of specified outcomes by the macro-level

purchaser, the local manager (as well as provider) has no incentive to change practices--they simply need to operate within the total amount of capitated funds. Capitated arrangements pursued at the macro-purchaser level really only affect the redundancy and rising-cost aspect of non-market failure. However, for the micro-local purchasers, capitation simply places tighter parameters around the potential to maximize their budgets.

The second potential for non-market failure is the interrelationship of derived externalities and distributional inequity. Continued client systems dependency resulting from budget-maximizing incentives by controllers of the buy-sell arrangements, along with real or perceived community and/or client capacity concerns, create opportunities for unintended side-effects that result in the wrong persons benefiting. The ultimate and primary beneficiary is identified in public policy: in this case, individuals with mental retardation. A beneficiary may be most interested in achieving self-described outcomes, such as a more desired life situation (e.g., better income, educational opportunities, friendships). Arguably, the community itself is also ultimately a secondary intended beneficiary. One would suspect that the community would minimally demand increased citizenship (e.g., contributions including increased individual, economic self-sufficiency,

assumption of meaningful and valued roles and obligations, and abiding by the laws and norms of society).

The public and nonprofit organizations are intended residual beneficiaries. That is, members of their organizations benefit through economic income and community status resulting from the manner in which policy is structured. In the case of managing and providing services and supports for people with mental retardation, the institutional arrangements are described as government service (public providers), intergovernmental agreement (macro- to micro-public arrangements), and contracting or purchase of services (relationship between public managers and private providers).

Purchase decisions in these types of arrangements are controlled by residual beneficiaries in non-market systems, thus, there is at least a question as to the appropriateness of the benefit that is assumed by the residual beneficiaries and what is assumed by the intended beneficiaries. Excessive residual diminishes the allocation of funds to the intended beneficiary--the client. This is critical as the funds are limited to begin with while the client is economically-impoverished. Additionally, with reduced funds, the clients choices are also minimized. The more funds that flow to the client, the broader the scope of opportunities the client will have in making purchase decisions. Furthermore, as the

residuals to the organization decrease and are transferred to the clients, the clients begin to assume the purchase power that is held by the organization.

Client control of resources and the assumption of greater responsibility are the two key principles of self-determination. Developing a relationship with the natural community (e.g., people and places) as related to the continuous improvement of the quality of their own as well as the communities' lives is a fundamental assertion of community inclusion (e.g., gainful employment, community service). In tandem, the client makes responsible purchasing decisions that would lead to outcomes of increased involvement with the natural community as a method of improving quality of life. Therefore, the client assumes the role of purchasing agent while potential sellers that may emerge include non-market (public entities and nonprofit organizations) as well market (for-profit firms) structures.

Client control of resources requires a different set of institutional arrangements (as compared to governmental, intergovernmental, and franchise institutional arrangements--all of which are controlled by the organization). The concept of clients being provided a set amount of financing within an individual support budget would be considered a voucher, thus allowing the client to freely make purchase decisions. Even if the institutional arrangements were more

restrictive, such as a grant arrangement, the client is afforded at least an opportunity to make purchase decisions by selecting from a defined set of alternatives. This practice would be comparable to the selection of a provider from within a provider network in a managed care arrangement.

Grant mechanisms do limit purchase options. In cases where the local public entity serves only in a manager's role and creates a provider network of non-public agencies (a franchising institutional arrangement), costs and regulated entry could be structured in such a manner that could potentially, once again, find residual beneficiaries (organizations) that assume an unintended proportional share of the benefit as compared to the intended beneficiary.

This analysis is not intended to presume that the simple empowerment of the client to make purchase decisions freely, together with the emergence of a mixed-market and non-market competitive model, will assure that the ultimate beneficiaries reap their full share of the intended benefit. Nor will the introduction of expanded opportunities for profit firms correct for market-related imperfections.

The alternative to non-market structures is a true market system--firms that engage in private transactions where both parties seek to gain value through the exchange. The single outcome measure of for-profit firms is profit.

Prices are set on assumptions of demand and return: Can I compete and make money? Therefore, poverty and general financial resource-constraint as factors influence opportunities to engage in market transactions (e.g., affordable housing). Furthermore, scarce demand prevents market firms from achieving a level of production that would allow lower economic classes from market access (e.g., adaptive technologies).

Markets, like their non-market counterparts, fail (e.g., they experience increasing rather than decreasing returns, they suffer informational inadequacies that result in parties to the transaction lacking critical information related to the exchange, and cause for the assumption of costs and benefits by parties external to the private transaction). Sound examples of market failure, as related to this instance, are imperfections resulting from informational inadequacies. Clients who lack life experiences, knowledge of opportunities and/or are discounted by influencing people and systems (e.g., families, professionals, organizations and communities' questioning of client capacities: disabilities defined as limiting) create informational inadequacies and/or inaccuracies. Circumstances could therefore result in purchase decisions actually reflecting excessive returns to the seller (another type of market failure--increasing

rather than diminishing returns) or simply needing the wrong mix of purchase to get to the clients' desired outcomes.

Supports and services for people with mental retardation are a public policy concern. Some contemporary thought involves "privatization" as a simple end-all to problems of governmental inefficiencies and the lack of promoting citizenship responsibilities. I mention this here to render caution to the reader. As stated earlier, self-determination and community inclusion could ultimately be described as privatization. However, this is only related to efforts that are intended to place resources directly in the hands of the intended beneficiaries who are impoverished, so that they may find expanded opportunities as well as power to make purchasing decisions related to the acquisition of supports and services. Privatization, as a mechanism of distancing government from people making claims and allegations against government, is not consistent with the principles of self-determination and community inclusion. Efforts to move away from public entities toward nonprofit organizations and for-profit firms as a mechanism for creating distance from matters of public accountability and social justice, and even economic efficiency for that matter, are not recognized as a practice inherently conducive to achieving the intended benefits of self-determination and community inclusion.

Organizational Arrangements

The first part of this systems area of analysis spoke to the constellation of market and non-market institutional arrangements that constitute the potential buy-sell arena. This area of analysis will focus on the individual organizations defined as the system responsible for implementing self-determination practices and pursuing community inclusion opportunities and outcomes.

As was apparent in this research effort, three (3) of the organizations were public entities--local community mental health systems responsible for managing comprehensive specialty supports and services for people with developmental disabilities. These local public entities may also be involved in the delivery of any or all supports and services, or they may ensure delivery is carried out by contracting with other systems, primarily nonprofit organizations, designating support and service delivery expectations. The fourth organization involved in this study is an example of one of these nonprofit organizations under contract with the local public entity to provide contractually-specified supports and services.

The literature reviewed supported the notion that there would be varying perceptions of organizational members relative to their position within the organizational

structure (Katz and Kahn, 1978; Henery, Keys, and Balcazar, 1996; Marrone, Hoff, and Helm; 1996). The literature focused on organizations as comprised of leadership (policy formulators) and line (policy implementers) functions. This research effort expanded on this perspective by further dividing organizations into members who are directly related to the purpose of the organization and those who are involved in functions intended on supporting the purpose of the organization. Thus, this research effort was intended to more discreetly examine not only the horizontal nature of organizations, but also provide a vertical perspective. That is, the identification of commonalities and variations between the leadership (CEOs, Board Members, Program Managers, CFOs, administrative management staff) and line (client support coordinators, non-management administrative staff) members of organizations as well as between those members involved with the purpose of the organization (direct: CEOs, Board Members, Program Managers, client support coordinators) and those members involved with supporting the purpose of the organization (indirect: CFOs, administrative management staff, non-management administrative staff).

The quadrant approach applied was intended to provide an examination of organizations to get at the variation in interests, experiences and responsibilities within

organizations. Quadrant #1 (leadership/direct) and quadrant #2 (line/direct) are responsible for directly implementing the purpose of the organization (e.g., delivering goods and services). Quadrant #3 (leadership/indirect) and quadrant #4 (line/indirect) are responsible for supporting the organization's pursuit of purpose. Leadership organizational members (quadrants #1 and #3) serve as purpose or support formulators, while line staff serve as purpose or support implementers.

Formulation speaks to the organization's vision, mission, values, policies, and plan. Implementation speaks to the organization's procedures, practice protocols and actual application. The evaluation function loops through organizational leadership members (e.g., quality improvement practices; internal and external oversight efforts) to be applied by staff serving in line roles.

Although the organizations are dissected into quadrants, the manner in which the whole comes together is critical. That is, an organism operates in concert: each component contributes and acts in a manner that effects the conditions of the overall organism.

The literature reviewed as well as the research effort itself revealed inconsistent perceptions and practice concerns among leadership and line organizational members. The literature review as well as this research effort showed

less inconsistencies in perceptions between direct and indirect actors. This may be attributed in part to the lack of literature concerning the empirical investigation of the direct/indirect aspect of organizations.

As for the research at hand, all of the organizations were involved in a defined project (RWJ Self-Determination initiative) and participants were selected in a manner that would allow for individuals most familiar with and knowledgeable of the initiative to participate in the research. Furthermore, the initiative represented a subsystem of the larger organization since the organization's purpose was much broader than the scope of the initiative. Therefore, the potential for consistency between all participants across all organizations was high, at least in what was expressed verbally and in writing by the participants. Variations and inconsistencies would logically become more evident in the written materials reviewed as reflections of potentially organization-specific features.

The variations in perceptions between leadership (CEOs, Board Members, Program Managers, CFOs, administrative management staff) and line staff (client support coordinators, non-management administrative staff), particularly as related to the process of moving from the conceptualization to the practice of the concepts, were of

great interest. Leadership and line staff reported divergence in comparative perspectives of the manner in which they believed the organization was operating as implementers of self-determination and community inclusion. Documentary evidence reviewed suggested that the organizations were very strong in establishing relevant conceptual values. It was the practice-related evidence that reflected some drift away from the manner in which the concepts were intended to be operationalized.

The responsibility for the organization's conceptualization of self-determination and community inclusion resides with leadership staff. This responsibility includes assuring that all organizational members are familiar with and committed to the concepts. The leadership is also responsible for defining roles and expectations and allocating resources consistent with the purpose of the organization--all which ultimately serve to support practices conducive to the operalization of the concepts. The findings in this study suggest that this has occurred for the most part. However, the study is limited in its ability to determine if the transference of the values was a result of formal, organizational, leadership efforts and/or through other methods of acquisition (e.g., informal organization, external stakeholder influences, etc.).

Blanket claims that the leadership failed in its

concept-related execution responsibilities cannot be empirically substantiated. In fact, evidence demonstrated that leadership established practices that promoted and supported self-determination practices and the pursuit of community-inclusive opportunities and outcomes (e.g., person-centered planning protocols; individual support budget processes; allocation of financial resources to individuals as opposed to programs; the implementation of support models of practice; and the provision of relevant substantive training). At the same time, citing line staff for failing to properly implement the concepts is also empirically unfounded. There was evidence that staff were implementing the concepts (e.g., people in attendance at planning meetings; clients securing jobs and housing in the community).

The issue of the differences in perceptions between the leadership (CEOs, Board Members, Program Managers, CFOs, administrative management staff) and line (client support coordinators, non-management administrative staff) staff is a key finding. The nature of the finding that each group seemingly indicating that the other group is not "doing their job" suggests that the purview of organizational members is mostly limited to within the scope of their own roles and functions. That is, the individuals understand what they are responsible for and can only assume what

others are to do. However, these findings could not be categorized as simple assumptions that all shortcomings are the fault of others. In this instance, the two groups are accurate in the assignment of responsibility. Perceptions of the assignment of responsibilities to leadership for assuring matters such as policy support for clients to control resources and line staff responsibilities to assure the desires of clients are pursued in planning efforts are accurately assigned to the appropriate parties.

What is of the greatest interest here is that each group seems to reflect accurate understanding of the role and functions of the other organizational members. This is a real strength as related to the organization's comprehensive ability to communicate expectations. This may also contribute to the organization's ability to "speak the same language" regarding the concepts of self-determination and community inclusion across and between the agency. Although the perceptions may lack some accuracy, which is supported by evidence from other sources (e.g., focus groups, content analysis), there is a solid foundation of understanding of expectations of roles, responsibilities, and functions and of the concepts themselves from which to build a more consistent and more importantly, accurate, collective perception.

There are two factors which may best explain the

variation between leadership and line staff as well as the divergence between concept and practice. The first is reflected in time, history, and experience. The second, which could be argued as related to the first, involves the fundamental nature of organizations--organisms comprised of formal and informal structures.

The self-determination initiatives were at an early stage. The organizations selected to participate in this endeavor have been formally involved in this effort for no more than four years (including start-up efforts). These initiatives involve a radical departure from traditional practices. Therefore, the duration of the organizations' formal involvement with a very different way of doing business suggests that implementation of related activities may not have sufficiently matured. The term "formal involvement" is stressed because this research effort did not examine any relationship between current efforts and past practices. In other words, some organizations may have already been operating in a manner similar to the requirements of the self-determination initiative (or, for that matter, in a manner completely contradictory to the intentions of the initiative).

Along with the observable formal structure of organizations, the "unwritten" informal organization exists. Theoretically, the informal organization enjoys

decision-making power relinquished by the formal organization which, in turn, establishes the parameters in which decisions are to be made (e.g., as manifest through the allocation of resources and the nature of the environmental context) (Cyert and March, 1963). The informal organization may have (as delegated or "taken" from the formal organization) less, equal to, or more power in comparison to the formal organization. These two structures may function as supportive or oppositional to each other in any or all matters. Both forces maintain abilities to reward, punish, and control members through sanctions. Both the formal and informal systems maintain communication patterns with the formal organization primarily engaged in exercising voice through formal channels (e.g., chain-of-command, written policies) (Simon, 1976).

The study was not specifically designed to delineate the organization as a formal or informal organism. However, the methodology applied, particularly the survey, and to a lesser extent the focus groups, did allow a mechanism for the informal organization to "speak." The leadership's more negative perception, as compared to line staffs, regarding the adequacy in the application of client-level planning efforts, and the line staffs' more negative perception compared to that of the leadership staff relative to the organizations commitment to client resource command and the

pursuit of community-inclusive outcomes, says something about the "informal" organization. It's a matter of roles and expectations. Each group is indicating that the other may not be performing their roles and expectations in a manner they believe is adequate. At the same time, both groups concur on external, constraining forces (e.g., guardians, families, communities, regulations), which suggests a unified perception of factors external to the organization that hampers their abilities to carry out their roles and fulfill their expectations.

Summary of Analysis

The organizations involved in this research effort clearly demonstrated sound commitment and competency in conceptualizing and implementing self-determination practices and pursuing community-inclusive opportunities and outcomes for people with mental retardation. This was demonstrated particularly through their alignment with the values and knowledge of these concepts. Although there were some problems discovered in the application, methodological considerations (limitations of this study) and other extraneous factors not controlled (e.g., time, history and experience) serve as caution in making any absolute assumptions regarding the findings. However, the evidence reflecting some shortcomings in the practical application of

these concepts was minimal.

There were differences in perceptions between leadership and line staff in two critical areas: the self-determination related concept of resource control and the community-inclusive related concept of inclusive outcomes. These are termed as "critical" because they are both essential elements of the concepts as well as the ultimate bridge between the concepts. The individual's ability to control resources leads to avenues of selecting purchases that could find buy-sell transactions in market and non-market systems not part of the current providers of supports and services.

Expanded opportunities potentially available to clients through real control of financial resources promotes both self-determination (e.g., client as the determinant of purchases) and community inclusion (e.g., client assuming a valued role as a customer in the community). This also leads to a cycle of advancing these concepts and includes the community building more capacity to respond to specialized needs as demand becomes apparent.

To create expanded opportunities for clients to assume purchasing power and ultimately achieve community-inclusive outcomes, contemporary institutional arrangements will need to be changed or abandoned for alternatives. For example, public monopolies and private franchise arrangements would

need to give way to vouchers. Thus the real movement of funds from programs to clients will occur. This movement would require internal change (the manner in which organizations provide and arrange supports and services) as well as external change (the emergence of community responses to new demands and potential regulatory reforms, particularly as related to clients controlling public funds).

This concept of forces to be contended with ("barriers") found concurrence between leadership and line staff; however, the scope of their agreement was limited. Organizational members cited general community barriers (e.g., social norms) and specific groups of people as obstacles (e.g., guardians). They did get at some concrete issues, such as transportation, housing and employment concerns, as well as poverty. These substantive concerns move closer to reflecting a more sophisticated understanding of the most compelling issues. These issues include clients being provided decision-making power as related to access to natural exchanges of goods and services in the community, as well as the interaction with people in these transactions--the fundamental expression of self-determination and community inclusion.

CHAPTER 6: RECOMMENDATIONS

Before framing the recommendations, this researcher first must acknowledge the efforts of the organizations involved in this study. All four organizations were more than cooperative participants. These systems (and people) graciously opened their doors and hearts to be closely examined. Additionally, these organizations demonstrated great commitment and capacity in carrying out the practice innovations related to self-determination and community inclusion. These systems are to be applauded for their commitment to both learning and practice.

The brief recommendations offered are framed into four components. First, potential replication variations of this research effort are presented. Second, a design intended to examine correlations between self-determination practices and community-inclusive outcomes is described. Third, key learnings derived from this research are presented as recommendations for field application. Fourth, both concepts are organized in a strategic manner to guide future field and research considerations.

Replication

Although a number of limitations of this research effort were identified (e.g., sample size, sampling

methodology), there were also several strengths that warrant consideration of replication (e.g., survey instrument reliability). A straight-forward replication of the study as it was designed would begin to alleviate several limitations, particularly as related to sample size and general interater issues and as related to the focus groups and content analysis. Additionally, modified replications would allow for a comparative analysis between or within organizations. Furthermore, replication could be taken out of an organizational context and used with primary beneficiary groups.

Two variations of a replication of this study may produce additional understanding of organizational change as related to implementing self-determination practices and community-inclusive opportunities and outcomes. In a between-organization model, the inclusion of comparable non-RWJ sites may render a better understanding of the extent to which RWJ-supported organizations were aligned more closely with the values, knowledge, and practice of self-determination. A within-organization study including comparable non-RWJ clients would provide a perspective regarding the outcomes achieved using the self-determination intervention in comparison to interventions typically applied by organizations. This later design could also be applied over time to begin to examine if the

self-determination intervention begins to transfer into the routine interventions (or, if the opposite occurs).

Replication could also be taken outside of organizations and applied to other groups. For example, excluding the content analysis portion of the study, families and/or clients could be the focus of study. This design could provide information concerning the perceptions of primary beneficiary stakeholders as related to the manner in which they perceive the organization is in pursuing self-determination practices and community inclusion (survey component) as well as gain an understanding as to how these individuals define and describe the concepts (focus group component).

Concepts

An area of potential study would involve an examination of the correlation between self-determination practices and community-inclusive outcomes. The practice of self-determination involves the application of person-centered planning encouraging the involvement of a variety of people described as "non-professionals." These include family members as well as acquaintances and friends ("ordinary people") from the community. Additionally, these planning efforts are intended to focus on the improvement of the quality of an individual's life, particularly as related to

making connections with natural places in the community. Therefore, it is plausible to suggest that the practice of self-determination is correlated with people achieving community-inclusive outcomes.

One could argue that a causal connection could be explored. That is, self-determination practices lead to community-inclusive outcomes. Although pre/post quantification of community inclusion outcomes could be accomplished (community-inclusive activities pre-intervention versus after a period of time post the intervention), there could be a good deal of difficulty in controlling for critical extraneous factors. For example, an individual's support network prior to the intervention may better explain the achievement of community-inclusive outcomes. Also, the types of desires expressed by an individual may be incompatible with the offerings of the community in which he/she lives.

Applied

The first applied recommendation involves the organizations' efforts to monitor the practice of the concepts. As the research revealed, overall the organizations articulated the values and demonstrated knowledge of the concepts relatively well. The divergence was most evident in the practice, or application, of

self-determination and community inclusion. It may be of benefit to examine the organizations' continuous quality improvement systems. The focus of such an effort would examine the sufficiency of performance feedback loops (e.g., client satisfaction, improved quality of life, community-inclusive outcomes) and response paths (the manner in which the organizations' apply performance-related learning), particularly as related to the operalization of these concepts. This practice of Total Quality Management (TQM) is intended to continuously, empirically examine performance and processes and seek improvements in order to best achieve desired outcomes. As such, it would include examining processes such as person-centered planning.

The second applied example is related to the critical practice areas where the leadership and line staff have divergent perspectives regarding the organization's performance. These areas involved person-centered planning, client resource control, and community-inclusive outcomes.

As perceptual issues, one can't assume that neither the leadership nor line staff are accurate in their portrayal of these matters. The TQM approach offered as the first applied recommendation would allow for systematically determining the organization's performance in these areas. However, even if the organization is pursuing these practices and outcomes in an exemplary manner, the perceptual issue may not go

away.

All of the organizations indicated that their staffs have had training in the key concepts: self-determination, community inclusion, and person-centered planning. Although line staff were more likely to have received training, there were some variations between the organizations in this regard. What might be most helpful is the development of a strategic training program that considers the following:

1. Combining line and leadership staff as participants in collective learning events. This would require the learning agenda to be structured in a manner that not only accommodates the interests of each individual group, but that integrates their issues into a package that would allow the learners to understand the connection between micro- and macro-practice.

2. Delivering learning in a manner that would include didactic as well as experiential instruction. This would include "live" (real and current issues people are struggling with) problem solving both in case-level issues as well as in systems concerns.

3. Allowing sufficient time and resources. This includes duration over the course of time inherent in a strategic approach intended on promoting planned change. Also, a commitment to prepare, attend and participate in the educational events would need to be assured. Therefore, the

adequate allocation of resources in these efforts would include not only experts to facilitate learning (or, at least the potential need for such resources) but also distribution of routine workloads and assignments in such a manner that would assured sufficient time for the preparation and attendance of the participants without negative consequences after their return. Ongoing support would also be required from leadership in assuring that practices of the organization actually achieve planned change resulting from the learning.

Strategic

If ultimate self-determination and community inclusion involves people exercising citizenship through engaging in market transactions, there is a need for a comprehensive examination of the various impediments to this process. There are six key forces comprised of people, circumstances, and systems as a constellation of relationships that create barriers to clients truly controlling financial resources in making purchase decisions and the ultimate emergence of markets.

First, the issue of poverty results in an individual's acquisition of resources as a type of direct transfer payment subsidy from an organization funded to manage and/or provide supports and services. Of course, if

community-inclusive efforts ultimately lead to the individual becoming gainfully employed, they may need only limited subsidy or none at all. However, for people with severe disabilities, at least a portion of the resources necessary for support that would be designated as under their control will be public funds.

The second factor that is a potential impediment to clients' controlling financial resources are manager and provider organizations. Barriers to self-determination practices and community-inclusive opportunities and outcomes perceived by research participants in the focus groups included organizations that provided traditional programming who stood to lose funding if clients elected not to purchase their services. These organizations, particularly the entities charged with ensuring the provision of services (recipient of state and federal funds and holder of a public mandate), have an incentive to minimize liberalization of the market as these organizations gate-keep market entry. Granted, a client controlling resources and making purchase decisions influences market entry. But it is the systems that control the larger sum of money that have the real purchase power--the depth and breadth of economic force--which influences the emergence of markets. This is particularly the case as only a limited number of clients are involved in self-determination efforts.

Regulations constitute the third force with which to be contended. Limitations on placing public funds directly into the hands of clients is mitigated through the use of fiscal intermediaries. Although these systems arguably may be described as "disinterested third parties" in terms of potential gain-based incentives, they are yet another step between the purchaser and seller.

The fourth element in this strategic picture is the individuals who hold formal and/or informal power over the client. Excluding professionals involved in providing supports and services (as they are considered as part of organizations) these individuals have been vested with a legal authority (e.g., guardians, parents of minor children) and/or are recognized by people, including the client, as having control (e.g., parents, friends). These individuals influence decision-making, either intentionally or unintentionally, which may serve to influence a client's purchasing decisions. Granted, all people are influenced by others in making decisions as this includes the process of gathering information prior to making a decision. However, influence in this instance may include perceptions of disabilities as limitations. For example, a client may wish to purchase a lesser amount of in-home staffing as they are totally willing and capable of providing for particular self-care needs. Family members may influence the individual

into believing that, due to the disability, he/she cannot take care of these needs independently, thus the client ends up purchasing supports that are really not needed.

The client would be considered the fifth impediment to the process of making purchase decisions. Lack of life experiences, the exercise of excessive controls by others, and comfort with what is known, in conjunction with limitations in opportunities resulting from the other barriers presented in this section, potentially serve to severely constrain purchasing decisions.

The sixth constraint to the client as purchaser is the community--the natural market. If there is no demand for a good or service, there is no market. If there are inadequate resources necessary to make purchases (e.g., poverty related) or if the cost structure reflects only limited demand (particularly as related to goods or services that will naturally have limited demand--wheelchairs, as an example) it will result in non-market structures being established in response to a public-policy need.

Self-determination interventions need to carefully consider these six forces in developing a strategic response. While self-determination principles do address these concerns, if they are only applied in a micro-tactical sense, the systems-based changes will most likely not occur. As was demonstrated, the findings in this research effort

repeatedly pointed to these forces as impediments. Although organizational-level planning efforts were revealed in the research, most of the energies were on individual cases as the catalyst to change, not on systematic, structural features.

Certainly, case-level change tactics are important. However, they should be part of an overall strategic change effort. The only strategic exception is the use of a fiscal intermediary as a response to regulatory barriers. This may be too distant for a local system, organization, or community to address (e.g., state and federal policy related). The remaining five elements should be included in a planned change strategy: the construction of more sophisticated research designs, community organizing and capacity building efforts, and training activities (for all stakeholder groups). A strategic approach of this nature will provide a better path to the ultimate conceptual understanding and realization of self-determination and community inclusion--full citizenship for people with mental retardation.

APPENDIXES

APPENDIX A

RECRUITMENT LETTER

Richard James Visingardi, MSW, MPA
6225 Rosedale Road
Lansing, Michigan 48911
517-394-1352

[Date]

[Name of CEO]
[Name of Agency]
[Agency Address]

Dear [Name of CEO]:

I would like to begin by thanking you for your willingness to be a participant in this research effort. Your involvement in the development of knowledge in this area demonstrates a real and expansive commitment to supporting and serving people with developmental disabilities.

As evident in my dissertation prospectus overview that I shared with you, the focus of this research endeavor is on the manner in which organizations support and serve people with mental retardation. Specific to this effort is the application of self-determination practices and the advancement of community-inclusive outcomes for this population.

As also presented in the prospectus overview, organizations and their members (staff) will serve as the study's subjects. A group of thirteen voluntarily consenting persons will need to be secured to complete an individual pen and pencil survey and participate in a focus group. Additionally, this research effort involves content analysis. Thus, there are several source documents I would need to secure. All of these source documents would be considered public, non-confidential and/or not protected (as related to risk management considerations) resources with the exception of consumer support plans.

Release of these plans to me will require adherence to the recipient rights provisions of the State's Mental Health Code. From a research ethics standpoint, it should also be noted that this entire effort is being overseen by my Doctoral Committee and has been approved by the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University.

To move forward in this process, there are several tasks that need to be completed. During the week of November 15th, I will be in contact with you, or your delegate if you so desire, by phone to address the following:

Questions and Concerns

I will first provide you with an opportunity to present any questions or concerns that you have regarding this research effort as well as the role of your organization. I have also attached a revised prospectus overview. Revisions of this document were minor and primarily involved methodological considerations that are also incorporated into this letter. I will review these modifications with you as part of our phone call.

Scheduling Site Visit

I will need to secure a site visit date. I am working with four sites and have an eight working day window for scheduling site visits (December 1, 1999 through December 10, 1999). Along with the date and time, I will need instructions to the place where the visit will occur. The area required will need space sufficient to seat people comfortably and organized for the survey component of the visit (writing surface for all thirteen subjects at one time) and a circle arrangement to seat ten persons for the focus groups. If available, I will also need a flip chart and markers (if this is not available, please let me know).

Identification of Subjects

I will review with you the specific subjects that I need to have involved in this effort (CEO, CFO) as well as the classification of other subjects that are needed, as described in the organizational quadrants presented in the prospectus overview. As you will note, I am interested in position types, thus, once these are identified you may recruit persons to participate. I will need a copy (unduplicated) of the current job description of each participant. I can pick these up at the time of my site visit.

Consumer Support Plans

I will need the most current support plans for four consumers with mental retardation currently involved in your self-determination initiative. In seeking release of information for these plans, please note that all names and potential identifying information should be deleted. Additionally, these plans will only be reviewed by myself and one research assistant and will be handled and disposed of in a manner that will protect the individuals' identities. I will pick up copies of these at the time of my site visit.

Resource Documents

As presented in the prospectus overview, there are a number of source documents that I will need to complete the content analysis component of this research effort. I will need the name of a contact person as well as a scheduled time to make a phone contact with this person to go over these items. I would assume that the phone contact should not exceed thirty minutes.

It should be noted that I will be making every effort to scope the securing of the source documents in a manner to assure that only the most relevant items are provided in an effort to gain the greatest time efficiency for both of us, minimizing the quantity of paper involved and maximizing the targeted relevance and importance of the sources identified. Thus, it would perhaps be best if the contact person you select be knowledgeable about both the self-determination initiative as well as the broader practices of the organization. I will pick up copies of these documents at the time of my site visit.

Return Considerations

There are three items I would categorize as "return" related. First, I will reimburse your organization for the cost of your clerical staff to copy the source documents and consumer plans as well as the copying charges. Secondly, in an effort to best use time, I can reimburse you for purchasing lunch to be served for each of the focus groups. If we decide on lunch, I will work out the arrangements to assure that there are no potential methodological or timing problems. Thirdly, prior to the last three chapters of my dissertation being finalized, I can make arrangements to return to your organization to present, discuss, and gain additional perspective of the draft findings, analysis, and recommendations.

If you have any questions or concerns, please contact me at (517) 394-1352 (home) or (517) 335-0252 (work).

Once again, I thank you for your willingness to participate in this effort. I look forward to speaking with you the week of November 15th.

Sincerely,

Richard J. Visingardi, MSW, MPA
Doctoral Candidate
Michigan State University
College of Social Science
School of Social Work
Department of Political Science

Attachment (2)

DISSERTATION TITLE: THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE ACHIEVEMENT OF COMMUNITY-INCLUSIVE OUTCOMES FOR PEOPLE WITH MENTAL RETARDATION

The following are taken from Chapters #1 (Literature Review), #2 (Specific Aims), and #3 (Methods) of the Dissertation Prospectus of Rich Visingardi.

INTRODUCTION

There has been a sustained evolving concern for promoting the rights and responsibilities of full citizenship for people with developmental disabilities over the second half of the twentieth century (Parham, Hart, Newton, and Terraciano, 1983; Moss, 1984; Menolascino, Gilson, and Levitas, 1986; Chiles, 1987; Plum, 1987; Holbrook and Percy, 1992; Perlin, 1994; Pfeiffer, 1993; Tower, 1994; Weber, 1994; Weber, 1994; Henry, Keys, and Jopp, 1996; Mackelprang and Salsgiver, 1996; Huang and Rubin, 1997; Fleischer and Zames, 1998; Nerney, 1998). Self-determination and community inclusion are contemporary philosophies and practices intended to promote an individual's right to be a full participant in natural community processes and places (Mount, Beeman and Ducharme, 1988; Perske and Perske, 1988; O'Connell, 1988; Amando, Conklin and Wells, 1990; Sullivan, 1992; Harper, 1996). In developing an understanding of the concepts of self-determination and community inclusion, this literature review is organized into three components: concepts, framework, and context.

Conceptual Considerations

Self-determination and community inclusion are the concepts being defined. Self-determination is developed through a set of principles that place individuals with disabilities as driving her/his life desires and decision-making, controlling resources intended on providing for support and accommodation, and involving other people whom the individual has identified as significant in her/his life (O'Connel, 1988; Hoffman and Field, 1995; Wolfe, Ofiesh, and Boone, 1996; Nerney, 1998). Person-centered planning offers a methodology for pursuing the development and related actions of self-determination practices (Heller, Factor, Sterns, and Sutton, 1996). Thus, person-centered planning is intended to be the conduit for self-determination.

Community inclusion are outcomes associated with an individual acquiring access and opportunities in the mainstream of community life (Peterson, 1993). These opportunities are related to the development of relationships with people and places in

the natural community (Mount, Beeman, and Ducharme, 1988; O'Connell, 1988; Amando, Conklin, and Wells, 1990; O'Brian and Lovett, 1992; Mount and Zwernik, 1994; McNulty, Connolly, and Wilson, 1996). Theoretically, it is proposed that the engagement in self-determination practices will lead to increased community-inclusive opportunities and experiences.

Framework Considerations

The framework presented serves as the boundary in which self-determination and community inclusion operate. These parameters include historical, policy, economic, social, and ethical considerations.

Over the past fifty years there have been on-going efforts to move away from large segregated facility-based institutional arrangements of care to providing services and supporting people within the community (DeWeaver, 1983; Lakin and Bruininks, 1985; Bachrach, 1989; Wadsworth, Harper, and McLeran, 1995; Stancliffe and Lankin, 1998). This evolution from institution to community is supported through current public policies such as the Americans with Disabilities Act of 1990 (ADA), as well as through judicial interventions (Parham, Hart, Newton, and Terraciano, 1983; Moss, 1984; Chiles, 1987; Plum, 1987; Holbrook and Percy, 1992; Perlin, 1994; Pfeiffer, 1994; Tower, 1994; Weber, 1994; Henry, Keys, and Jopp, 1996; Mackelprang and Salsgiver, 1996; Huang and Rubin, 1997; Fleischer and Zames, 1998). Economic consideration is central to public policy pursuits as they change the incentive structure for financing service and support systems (Mount, 1990; O'Brian, 1991; Rimmerman, Botuck, and Levy, 1996; Nerney, 1998). Policy is carried out through social efforts and actions. Specific to disabilities, the socialization process may be hampered as a result of the stigma associated with disability labels (Evens, 1983; Poole, Regoli, and Pogrebin, 1986; Stiles and Kaplan, 1996). Finally, the concept of self-determination itself is subject to ethical tensions between clients and professionals as well as within service and support organizations and communities (Reamer, 1983; Rothman, 1989; Walden, Wolock and Demone, 1990; Fleck-Henderson, 1991; Regehr and Antle, 1997).

Contextual Considerations

Families, interpersonal relationships in the community, service and support organizations, and ordinary places within the community form the context in which self-determination and community inclusion occur. Contextual factors are the set of relationships between people and places that influence the manner in which the concepts play out.

Support demands on families with a member with a disability are apparent throughout the family life cycle and are a source of stress (Schreiber, 1984; Lustig, 1996; Lefley, 1997; Seltzer and Heller, 1997). Developing a network within the natural community provides opportunities for people with developmental disabilities to expand supportive, meaningful, and reciprocal relationships beyond their families (Mount and Zwernik (1989; Nisbet, 1992; Mank, 1996; Rogan, 1996). Human service agencies charged with providing supports and services for people with disabilities and their families are faced with developing organizational values and competencies for adopting the philosophies and practices of self-determination and community inclusion (Mount, 1990; O'Brian and Lovett, 1992; Shifting Patterns, 1992; Wolfe, Ofiesh, and Boone, 1996; Henry, Keys, and Balcazar, 1996; Harper, 1996; Smull, 1998). The natural community provides three key ordinary places where individuals are provided opportunities for advancing their citizenship: housing, employment, and school.

PROPOSED SCOPE OF INQUIRY

Organizations involved in the implementation of self-determination policies and practices for people with developmental disabilities are influenced by the contextual and framework forces described in the review of literature. These forces are both internal and external to the organization. Internal forces include the organizational staff as individuals with diverse characteristics, beliefs, knowledge, and experiences and the manner in which these factors shape the organizational environment. External forces include policy, social, and constituent expectations that also serve to influence the nature of the organization. Furthermore, the relationship and interactions between internal and external forces, consistent as well as conflicting influences, provide the dynamic energy for continuous organizational evolution.

The focus of this proposed research effort is on the internal aspect of organizations responsible for providing or arranging supports and services for people with developmental disabilities. The concepts central to the specific aims are as follows:

(1) Self-determination (as a set of practices).

(2) Community inclusion (as a set of outcomes).

It should be also noted that the concept of person-centered planning is included as a component of self-determination practices.

Self-determination and community inclusion are first established in theoretical terms as philosophies and as conceptualized in public policy. These concepts each form a fundamental values base from which responsible organizations develop methods of implementation. The process of implementation is defined in two sequential and related components. First, the agencies need to, initially and on an on-going basis, assure that members of the organization develop concept relevant values and knowledge. Second, the organization is responsible for implementing, monitoring, evaluating, and continually improving practices conducive to self-determination and the achievements of community-inclusive outcomes. Competencies, as related to individual organizational members as well as the organization as a whole, are established within the scope of values, knowledge, and practice.

Thus, these three factors associated with each of the concepts, and the proposed research interest, are as follows:

(1) Values: Belief system regarding the concepts being studied (interest in degree of accuracy).

(2) Knowledge: Understanding of elements, constructs, and applications of the concepts being studied (interest in degree of consistency with the values and level of accuracy in understanding).

(3) Practice: Self-described activities that are intended to reflect the operalization of the concepts being studied (interest in the degree of consistency with the values, level of accuracy in understanding, and evidence of the concepts being carried out).

Research Questions

The three proposed research questions are as follows:

(1) Is the overall organization, as a formal system, conducive to self-determination practices and the pursuit of community inclusion?

(2) Between the direct and indirect organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated with the concept of self-determination and community inclusion?

(3) Between leadership and line organizational members, are there differences in how the organization states values, demonstrates knowledge, and exhibits practices associated

with the concepts of self-determination and community inclusion?

The first question inquires as to the formal systems in place that provide evidence that the organization is directed and operating in a manner that supports and promotes each of the two the concepts. The second and third questions examine the organization from a vertical (direct and indirect organizational members) and a horizontal (leadership and line organizational members) perspective as related to each of the two concepts.

Organizational Philosophical Framework

Central to the research questions is the philosophical framework of the organization. The organization's philosophical framework is made up of the formal and informal normative standards as communicated, as manifest in relationships between human, financial, and technical resources and as exhibited through practice.

As related to the two concepts to be examined, the organization's philosophical framework is evident in the values, knowledge, and practices of the organization, as follows:

(1) Values: Conceptually stated in the organization's vision, mission, values statements, strategic plan, and policies and as articulated by organizational members.

(2) Knowledge: Substantively described in the organization's vision, mission values statements, strategic plan, policies, procedures, and practice protocols and as articulated by organizational members.

(3) Practice: On a micro-basis, observable in the client-level manner in which the concepts are carried out. On a macro-basis, observable in the overall manner in which the concepts are carried out.

Professional Characteristics

The characteristics of individuals that define the nature of their professional selves directly influences the characteristics of the organization and are deserving particular consideration as a potential extraneous factor. For example, as described in the review of the literature, there were several empirically based studies that described perceptual differences as well as commitment to self-determination and community inclusion related values for people with developmental disabilities between leadership and front line organizational members.

The following professional characteristics provided additional descriptive data:

(1) The current organizational position/capacity of the individual.

(2) The duration of time the individual has served in this current position/capacity.

(3) The duration of time the individual has served as a member of the organization.

(4) The duration of time the individual has served working with people with developmental disabilities.

(5) The duration of time the individual has served in the human services field.

(6) The types of positions/capacities the person has served in during their tenure in the field of developmental disabilities.

(7) The types of positions/capacities the person has served in during their tenure in the field of human services.

(8) The individual's credentials including undergraduate and/or graduate degree(s), relevant certification(s) and/or licensure, and/or other substantial general professional training/education.

(9) Relevant technical and/or substantive training in the area of self-determination.

(10) Relevant technical and/or substantive training in the area of community inclusion.

The above items one through three provide information regarding an individual's current status as well as duration as a member of the organization and movement within the agency. Items four through seven provide evidence of the variations in capacity and tenure of the individual in the field of developmental disabilities as well as general human services. Items eight through ten provide a description of the individual's general professional education as well as specific professional training as related to self-determination and community inclusion.

Personal Characteristics

The personal characteristics of the individual subjects are also considered as a potential extraneous factor; thus they serve as additional control variables. Although the literature revealed limited empirical efforts examining personal characteristics, there was a good deal of research evidence regarding the perspective of families with members with developmental disabilities. Thus, general demographics and relationship proximity with people with developmental disabilities are proposed to be considered within a set of personal characteristics of the subjects.

The following personal characteristics are proposed to be examined as control variables:

(1) Age.

(2) Gender.

(3) Race/ethnicity/culture.

(4) Inquiry as to whether the individual has a disability (and type of said disability).

(5) Inquiry as to whether the individual has/had an immediate family member (parent, sibling, spouse/romantic partner, and/or child) with a disability (and type of said disability).

The above items one through three gather general demographic information regarding the individual while items four and five serve to identify the proximity of the subject to disabilities.

SUBJECTS

Four (4) organizations will serve as the ultimate subjects of this proposed research effort. The description of subjects as well as recruitment, selection, and consent are provided in the following sections.

Description

Three (3) sample groupings are to be used which are identified and initially described as follows:

(1) Organizations (Groups): This is the ultimate sample base. A non-probability based approach will be used in securing the participation of four (4) organizations.

(2) Organization Documents (Artifacts): A non-probability based approach with participating organizations being required to provide specific documents.

(3) Organizational Members (As Individuals and as Groups): A non-probability based purposeful sample based on a stratification within the participating organizations.

Recruitment

A total of four (4) organizations will ultimately be needed for the selected sample. These organizations are defined as local, legal organizational entities involved in providing and/or arranging (via contracts and/or provider networks) supports and services for people with developmental disabilities.

In order to develop the sample pool, the researcher will identify and seek the participation of organizations operating within the state. These sites must be organizations serving in the capacity of a Robert Woods Johnson (RWJ) Self-Determination pilot site for at least the past two years (initiating no later than October 1, 1997).

During the recruitment stage, organizations will also be informed of their commitment to the research effort. Commitment is defined in terms of the consent, information, and timeline requirements including organizational member time and effort.

Selection

As described in the Off-Site Data Collection section of this chapter, each organization will be divided into quadrants. The following describes the nature of each quadrant and the subject types:

(1) Quadrant #1: Consumer support and service related/indirect/management roles. Leadership, administrative, and management staff responsible for the oversight of services and supports and service and support personnel (CEO and Board members included in this quadrant). Three (3) subjects will be selected. The CEO, a Board member (selection at the organization's discretion) and the person identified as the top administrator for supports and services for people with developmental disabilities.

(2) Quadrant #2: Consumer and service related/direct/line roles. Case Management, Support Coordination, Client Service Managers, Clinical staff, and community para-professional staff responsible for providing direct

consumer supports and services. Five (5) subjects will be selected. They will be a mix of professional and para-professional staff. The researcher will select by position while the actual participants will be identified by the organization consistent with the position selection parameters developed by the researcher.

(3) Quadrant #3: Non-consumer support and service related/indirect/management. Leadership, administrative, and management staff responsible for the operations of the organization including finance, personnel, and quality functions. Two (2) subjects will be selected. The person identified as the top finance manager and one (1) additional person. For the second subject, the researcher will select by position while the actual participants will be identified by the organization consistent with the position selection parameters developed by the researcher.

(4) Quadrant #4: Non-consumer support and service related/direct/line staff. Finance, personal, quality and other line staff responsible for providing direct support and services in the operation of the organization. Three (3) subjects will be selected. The researcher will select by position while the actual participants will be identified by the organization consistent with the position selection parameters developed by the researcher.

As evident above, there will be thirteen (13) members of each organization participating as subjects in this research endeavor for a total of fifty-two (52) subjects.

The development of quadrants within the organization is consistent with the literatures concern with variation in levels of commitment to values, such as associated with person-centered planning, between the leadership and direct implementers within the organization--the vertical delineation within the organization. Additionally, the horizontal aspect of the quadrants is an effort to examine commonalities and variances between organizational members most directly involved with consumers and those members most involved in supporting the operations of the organization.

In order to identify the subjects needed, the researcher will review each organizational structure and related job descriptions with the organizations CEO (or an individual they designate) and categorize potential participants into the quadrants.

The organization will provide the researcher with a copy of the organizational structure and the related job descriptions

(unduplicated) of the subjects who will participate.

Consent

There will be three (3) types of consents secured. First, each of the four (4) ultimately selected organizations will consent to participate during the subject recruitment stage. Second, the four (4) ultimately selected organizations will be required to secure the consent of four (4) consumers allowing the researcher to review their support and service plans. Third, at the time of the site visit, each of the thirteen (13) organizational members participating as subjects in the survey and focus group efforts will be required to consent to their involvement. A copy of the individual subject (organizational members) consent form is offered as an attachment to this document.

DATA COLLECTION

Data collection will occur in two stages and will include subjects as individuals and as a group as well as organizational resource documents (artifacts).

Off-Site Data Collection

As presented earlier, at the time of securing consent to participate, each organization will be requested to provide the following information (all items to be in their most current forms):

(1) Organization Description. This involves documents that summarize the organizations history, legal arrangement (public, nonprofit), jurisdiction (purpose, populations served, services, geographical area) and resources and related arrangements (budget, staff employed, contractual arrangements).

(2) Organization Vision and Mission Statements and Values.

(3) Organization Strategic Plan. In the event that there is no document identified as the organization's "Strategic Plan," a business plan or any other document identified as the organization's plan will suffice.

(4) Select Organization Policies, Procedures, and Practice Protocols. These are related to the development, implementation, and monitoring of support and service plans and the use of organizational financial resources and consumer access to said resources (e.g., vouchers, personal budgets, flexible funds).

(5) Other Reports. These include summary Total Quality Management (TQM) Reports for the past year. In the event that there are no documents identified as the organization's "TQM Report(s)," any other organizational report that speaks to process improvements, performance, and/or outcomes as related to the organization will suffice. Additionally, the most recent organization Annual Report as well as any most recent accreditation and/or state agency oversight reports will be required.

(6) Client Plans. A total of four (4) cases, one (1) each for an individual with profound, severe, moderate, and mild mental retardation will be secured. The organization must secure consumer consent, remove names and, for the self-determination sites, the client must be involved as a participant in the self-determination initiative.

In the event that the diagnostic criteria can't be satisfied (categories of profound, severe, moderate, and mild mental retardation), cases with the single diagnostic criteria of mental retardation will be acceptable.

It should be noted that each organization will identify four (4) consumers each to serve as subjects. Consumers as subjects are limited to simply allowing for a review of their plans and will require no direct face-to-face contact initiated from the researcher. Thus, there are a total of sixteen (16) consumer subjects involved in this research endeavor.

The researcher will reimburse the organizations for the actual costs associated with staff collecting and copying the materials to a maximum total of one hundred dollars ($100).

With the exception of the organizational description information (above item #1), a content analysis of the information will be completed with analysis summary information cataloged into a template instrument. The analysis will involve identifying values, knowledge, and practice evidence regarding the concepts of self-determination and community inclusion by resource and template items. Values, knowledge, and practice definitions are included in the Specific Aims chapter.

The organizational description information (above item #1) will be used to develop a comparative description of the organizations involved in this research effort.

On-Site Data Collection

On-site data collection will involve two (2) methods:

(1) Survey: Pen/pencil instrument completed by subjects with researcher present in the room. Subjects will be seated in a manner that they cannot see other subjects' responses. Survey completion will take approximately forty-five (45) minutes and will occur just prior to the focus group.

(2) Focus Group: Two (2) focus groups will be used. The first group will consist of the eight (8) subjects from the organization quadrants #1 and #2 (client support and service related), referenced as the client direct focus group. The second group will consist of the five (5) subjects from the organizational quadrants #3 and #4 (organization operations related), referenced as the client indirect focus group. Thus, there will be two (2) separate focus groups arranged relative to the vertical split of the organization.

Separately, each of the focus groups will discuss ten (10) items. Following completion of the survey, a fifteen (15) minute break will be allotted. The client direct focus group will then take seventy-five (75) minutes to complete the five (5) questions related to self-determination and the five (5) questions related to community inclusion. This process will then be repeated with the client indirect focus group.

The researcher and a research assistant will serve as the co-facilitators and scribes. The subjects will be seated in a circle and the researchers will be standing facilitating discussion and scribing on a newsprint visible to all of the subjects. The researchers will keep discussion on each topic to no more than approximately seven (7) total minutes. The facilitators will also be responsible for making efforts to best assure everyone's participation.

The use of the researcher and a research assistant is intended to increase inter-rater reliability. Immediately following the completion of the focus group efforts at each organization, the researcher and research assistant will meet to debrief. The debriefing will focus on identifying shared perceptions as well as identifying and reconciling differences necessary to complete the preparation of the focus group information for organization and analysis.

CONSENT TO PARTICIPATE AS A RESEARCH SUBJECT

You are being asked to participate in a research effort that will require you to complete a survey and participate in a focus group. Your participation, as a subject as well as in the completion of any part of the survey or input into the focus group, is strictly voluntary. In signing this form, you are stating that you consent to participate in this research effort which involves your willingness to complete a survey and participate in a focus group. This also confirms that you have been informed that the nature of this research effort involves the study of supports and services for people with mental retardation and that you understand that the information provided to the researcher will not be shared in name or any other manner that could reasonably cause you to be individually identified.

_____

Signature

_____

Printed Name

_____

Date

APPENDIX B

SELECTION LETTER

Richard James Visingardi, MSW, MPA
6225 Rosedale Road
Lansing, Michigan 48911
517-394-1352

[Date]

[Name of CEO]
[Name of Agency]
[Agency Address]

Dear [Name of CEO]:

I would like to begin by once again thanking you for your willingness to be a participant in this research effort. Per my phone conversations with you (AND/OR DESIGNE), I and my Research Assistant, (NAME OF RA), will conduct our site visit on **DAY, MONTH DATE, YEAR STARTING AT TIME PM AND CONCLUDING AT TIME PM.**

The site visit will initiate with a survey questionnaire (which will take no more than 45 minutes) to be completed by 13 of your organizational members in the following roles:

LISTING (BY POSITION) OF SUBJECTS

To complete the survey, these individuals will need to be seated in a single room with writing space and in such a manner that each participant cannot see how the others are responding.

Prior to the participants starting the survey, the following will occur:

I will introduce both myself and my Research Assistant to the group, as well as explain our roles.

I will review the Consent Form and ask the participants to sign them and turn them in (I have attached a copy of the Consent Form). Please share the Consent Form with the participants prior to the site visit to assure that all of the individuals are voluntarily consenting to participate. In the event an individual who has been identified to participate as indicated in the list presented in this correspondence does not wish to participate, please let me know so we may select a different employment position category.

I will provide an overview of what we will be doing during our site visit time period.

I will distribute the survey and walk through the major sections of said survey to provide instruction.

Immediately following the completion of the survey, there will be a 15 minute break and then a select group of participants will be assembled for the first focus group (participants in both focus groups will be the same people who were involved in completing the surveys). The composition of the first focus group will be as follows:

LISTING (BY POSITION) OF FOCUS GROUP #1 SUBJECTS

These individuals would need to be seated in a circle to participate in a 75-minute focus group that will be facilitated by my Research Assistant and myself. I will bring newsprint, markers and tape and will need to write on the newsprint while it is hanging on the wall (I will need a surface that will not be damaged by tape). Once this focus group has concluded, there will be a 15 minute break and I will assemble the second focus group to repeat the process (members of the first group will be asked not to share the discussion with members of the second group during this 15 minute break). The participants in the second focus group are as follows:

LISTING (BY POSITION) OF FOCUS GROUP #2 SUBJECTS

Once the second focus group has finished, the site visit will be complete and we will depart.

It should be noted that although the composition of the participants in the two focus groups cannot change, the time sequence can. For example, if the Board Member in unable to participate in the first session due to a scheduling conflict, I can switch the order of the two groups.

Also, as we discussed on the phone, at the time of my site visit I will pick up the copies of the organization documents and client support plans that are being used for the content analysis and/or methods description portion of my research. These items are described as follows:

> The most current job description of the organizational members who participated in the survey/focus group (for duplicate positions only one job description will be needed).
>
> Materials that summarize the organization's history, legal arrangement (public, nonprofit), jurisdiction (e.g., purpose, populations served, services, geographic area, legal mandate), and resources and related arrangements (e.g., annual budget/revenue sources, number of staff employed, what is purchased via contractual arrangements).
>
> The organization's vision, mission, and values statements (goals and objectives would also be included).
>
> The organization's strategic plan or general organizational plan (summary version).
>
> Select organization policies, procedures, and practice protocols (these would be items specifically related to self-determination practices and the pursuit of community-inclusive outcomes and should include items pertaining to the development, implementation, monitoring, and modification of client support plans).
>
> Other key organization reports (e.g., summary most recent annual report, summary most recent or annual TQM report, summary most recent accreditation report, summary most recent state or local key funding agent site review report and any other summary documents that speak to the organizations performance).
>
> A total of four clients' most recent support plans. All of these individuals would need to be

participating in the Self-Determination initiative and you would need to seek consent as required under the Recipient Rights provisions of the Mental Heath Code (please note, you may remove the client names from these plans). All of these individuals would need to have a diagnosis of Mental Retardation and, if at all possible, I would like to secure one individual each who have been identified with profound, severe, moderate and mild Mental Retardation.

As I indicated in our phone conversation, and if you so choose, I will reimburse your organization for the costs associated with gathering and copying the documents that I have requested. If you determine that these costs will exceed $100, please let me know prior to your completing this part of my request.

I will also need instructions to the site. You may leave me a message by my work voice mail (517-335-0252) or fax (517-335-6775).

If you have any questions or concerns, please contact me at (517) 394-1352 (home) or (517) 335-0252 (work). Additionally, if there is any information in this correspondence that does not reflect an accurate account of our discussions to date, please let me know. Furthermore, if any circumstance arise that would alter the description of what is offered in this correspondence (e.g., you are unable to secure the voluntary consent of one of the employment position types needed), please let me know as soon as possible so an alternative can be worked out.

Once again, I thank you for your willingness to participate in this effort. I look forward to my site visit.

Sincerely,

Richard J. Visingardi, MSW, MPA
Doctoral Candidate
Michigan State University
College of Social Science
School of Social Work
Department of Political Science

Attachment (1)

CONSENT TO PARTICIPATE AS A RESEARCH SUBJECT

You are being asked to participate in a research effort that will require you to complete a survey and participate in a focus group. Your participation, as a subject as well as in the completion of any part of the survey or input into the focus group, is strictly voluntary. In signing this form, you are stating that you consent to participate in this research effort which involves your willingness to complete a survey and participate in a focus group. This also confirms that you have been informed that the nature of this research effort involves the study of supports and services for people with mental retardation and that you understand that the information provided to the researcher will not be shared in name or any other manner that could reasonably cause you to be individually identified.

_____

Signature

_____

Printed Name

_____

Date

APPENDIX C

CONTENT ANALYSIS TEMPLATE

People...	Vision	Mission	Values	Strategic Plan	Policies	Procedures	Practice Protocols	Other Reports	Client Plans
1. Choose personal goals									
2. Realize personal goals									
3. Choose where and with whom they live									
4. Choose where they work									
5. Decide how to use their free time									
6. Choose services									
7. Choose their daily routine									
8. Participate in life in the community									
9. Interact with other members of the community									
10. Perform different social roles									
11. Have friends									
12. Remain connected to natural support networks									
13. Have intimate relationships									
14. Exercise rights									
15. Are afforded due process if rights are limited									
16. Are free from abuse and neglect									
17. Are respected									
18. Have time, space, and opportunity for privacy									

People...	Vision	Mission	Values	Strategic Plan	Policies	Procedures	Practice Protocols	Other Reports	Client Plans
19. Have and keep personal possessions									
20. Decide when to share personal information									
21. Have health care services									
22. Have the best possible health									
23. Are safe									
24. Use their environments									
25. Live in integrated environments									
26. Have economic resources									
27. Have insurance to protect their resources									
28. Experience continuity and safety									
29. Are satisfied with services									
30. Are satisfied with their personal life situation									
31. Decide who is invited to their planning sessions									
32. Decide where their planning sessions are held									
33. Decide the time their planning sessions are held									
34. Decide the frequency of occurrence of their planning sessions									
35. Decide who will facilitate their planning sessions									
36. Choose a spokesperson(s) (as applicable) for their planning meetings									
37. Invite non-professionals (friends, family and acquaintances) to planning meetings									
38. State their desires at planning meetings									

People...	Vision	Mission	Values	Strategic Plan	Policies	Procedures	Practice Protocols	Other Reports	Client Plans
39. Are provided opportunities to explore new life experiences									
40. Are provided opportunities for supported living arrangements as an alternative to residential programs									
41. Are provided competitive or supported work opportunities as an alternative to day programs									
42. Are supported in choosing a career									
43. Are provided natural socialization opportunities as an alternative to segregated group activities									
44. Disabilities are accommodated to assure community-inclusive opportunities									
45. Are provided supports to best assure community-inclusive opportunities									
46. Develop a set of planned outcomes based on their desires and to achieve real life outcomes									
47. Choose who will provide their supports and services									
48. Hire and fire persons providing their supports and services									
49. Provided control of the financial resources used to purchase supports and services									

APPENDIX D

SUPPORT AND SERVICE PRACTICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES/MENTAL RETARDATION SURVEY

I. INTRODUCTION

Please review this introduction carefully before you proceed with the completion of this survey.

I would like to begin by thanking you for participating in this research effort.

This survey is organized into six components (including this introduction). You are required to complete components two (II) through five (V). The sixth component (VI) will be completed by the Researcher (coding related). Make sure that you carefully review the instructions before completing each section. You should also complete each section sequentially. Thus, if you skip a particular item or items prior to the completion of a section, you should complete said item(s) before moving on to the next section.

There are no right or wrong answers to any of the items in sections II and III. These sections simply require your most accurate and honest understanding and/or perception of the items presented. There are "right" answers to sections IV and V as they relate to factual information known by you. In an effort to minimize missing data, in all sections it is important to complete all responses and in accordance with the instructions.

Your responses will be treated in a confidential manner. Prior to the completion of this survey you were provided a "Consent to Participate" form that you signed. This form cannot be aligned with any particular survey. Although some of the personal and professional characteristic information could serve as an identifier of an individual, please be assured

that completed data forms will only be reviewed and handled by the Researcher and a Research Assistant attending this site visit.

All ethical safeguards are in place to protect this information, maintain confidentiality, assure external anonymity and reporting in a manner that will not allow for alignment with any individual participant or participating organization.

As you complete this survey the researcher is available to answer questions. However, responses will not be provided regarding interpretations or meanings nor will the researcher engage in discussions regarding any of the items or concepts.

II. CLOSED ENDED SURVEY

This part of the survey relates to how you perceive the organization currently operates as well as how you believe the organization should operate. For each statement, circle a single number on each scale that most accurately reflects your perspective (make sure that you circle an exact number and not between numbers). Also note the term "consumer" is in reference to clients with developmental disabilities.

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
1.	For the purpose of planning meetings, non-professionals (individual(s) defined as closest to the consumer and as evident in verbal or nonverbal signals by the consumer) serve as spokespersons for consumers who may communicate in a manner not easily understood by others.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
2.	Planning meetings occur on an as needed basis as determined solely by the consumer (includes through their selected non-professional spokesperson, if applicable).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
3.	Consumers are solely responsible for selecting who will participate in their planning meetings.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
4.	Consumers solely select the location where their planning meetings will occur.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
5.	Consumers solely select the time when their planning meetings will occur.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
6.	Consumers solely select who will facilitate their planning meetings.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
7.	Consumer planning meetings are attended primarily by the individual's family members, friends, and acquaintances from the community (e.g., there are few or no professionals who attend).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
8.	Professionals involved in consumer planning meetings participation is secondary to the non-professionals involved (the consumer, family members, friends and acquaintances from the community).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
9.	The role of professionals in planning meetings is primarily to identify resources that are available to meet the supports and services identified as a result of the planning effort.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
10.	Planning meeting processes focus on the desires as stated by the consumer (includes through their selected non-professional spokesperson, as applicable).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
11.	Planning meetings are focused on the abilities of the consumer.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
12.	Planning meeting efforts are focused on developing solutions to potential barriers to the consumer in pursuing their desires.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
13.	Planning meeting problem solving reflects approaches that are intended to accommodate a consumers disability.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
14.	Planning meeting strategies are focused on supporting the consumer to pursue a quality life in the natural community.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
15.	Planning meeting discussions and efforts reflect both the citizen rights and responsibilities of the consumer.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
16.	Planning meetings acknowledge potential limited life experiences of consumers by interjecting proposed alternative opportunities to explore.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
17.	Support and service plans developed reflect the consumers personally stated desires (includes through their selected non-professional spokesperson).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
18.	Support and service plans developed include defined outcomes intended on promoting the consumers quality of life in the natural community.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
19.	Support and service plans reflect outcomes related to consumers developing and advancing reciprocal relationships with ordinary people in the community.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
20.	Support and service plans reflect outcomes related to consumers developing and advancing reciprocal relationships with natural places in the community (e.g., housing, employment, recreation, socialization, spirituality).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
21.	Support and service plans reflect reasonable responses to legitimate health and safety concerns (least intrusive, restrictive, and invasive).	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
22.	Consumers make decisions regarding the manner in which resources are used to purchase supports and services.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
23.	Consumers are provided control of the financial resources (including those provided by/through the organization) used to purchase supports and services.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
24.	Consumers have the authority to select the people who provide them supports and services.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
25.	Consumers have the authority to hire and fire the people who provide them with supports and services.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
26.	Consumers are provided supported living options as an alternative to residential programs.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
27.	Consumers choose where they will live.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
28.	Consumers choose who, if anyone, they will live with.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
29.	Consumers are provided competitive and supported employment options as an alternative to day programs.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6
30.	Consumers choose their career.	1 … 2 … 3 … 4 … 5 … 6	1 … 2 … 3 … 4 … 5 … 6

	STATEMENT	HOW THE ORGANIZATION **CURRENTLY** OPERATES	HOW THE ORGANIZATION **SHOULD** OPERATE
		1 ..... 2 ..... 3 ..... 4 ..... 5 ..... 6 Strongly Disagree ←----------→ Strongly Agree	
31.	Consumers choose where they will work.	1 ... 2 ... 3 ... 4 ... 5 ... 6	1 ... 2 ... 3 ... 4 ... 5 ... 6
32.	Consumers are provided natural community social options as an alternative to segregated social activities.	1 ... 2 ... 3 ... 4 ... 5 ... 6	1 ... 2 ... 3 ... 4 ... 5 ... 6
33.	Consumers choose whom they wish to socialize with.	1 ... 2 ... 3 ... 4 ... 5 ... 6	1 ... 2 ... 3 ... 4 ... 5 ... 6
34.	Consumers choose where they wish to socialize.	1 ... 2 ... 3 ... 4 ... 5 ... 6	1 ... 2 ... 3 ... 4 ... 5 ... 6

III. OPEN ENDED SURVEY

This section is intended to prepare you for participation in the focus group. What follows is a series of inquiries that require an open ended (narrative) response. For each item, simply write down your thoughts. You can keep these brief as they are intended to prepare you for the focus group. The gathering of this information on the survey form allows the Researcher to make sure that all perspectives are fully shared during the focus group. Thus, in addition to the newsprint materials developed during and as a result of the focus group, any statements included in this section not fully presented in the focus group will be considered in the data collection efforts.

Remember, you may keep your comments brief (e.g., two to three sentences, short lists). Also, please print or write legibly.

1. How do you define self-determination for people with developmental disabilities?

2. What are the essential elements of self-determination practices for people with developmental disabilities?

3. What are the key ethical challenges evident in the application of self-determination practices?

4. What are the key barriers to the application of self-determination practices?

5. What are the key opportunities in the application of self-determination practices?

6. How do you define community inclusion for people with developmental disabilities?

7. What are some key community-inclusive outcomes?

8. What are the key ethical challenges evident in the pursuit of community-inclusive outcomes?

9. What are the key barriers in the pursuit of community-inclusive outcomes?

10. What are the key opportunities in pursuing community-inclusive outcomes?

IV. PERSONAL CHARACTERISTICS

In this section inquiries are directed at your relevant personal characteristics which include traditional demographic questions regarding age, gender, and race/ethnicity/culture as well as the proximity of disabilities to you personally.

1. Indicate your date of birth:

Month	Day	Year

2. Check the block for your gender:

	Female
	Male

3. Check the block for the racial or ethnic group with which you identify:

	White (includes Arabian)
	Black (includes Jamaican, Bahamians, and other Caribbean's of African but not Hispanic or Arabian descent)
	Hispanic (includes persons of Mexican, Puerto Rican, Central of South American or other Spanish origin or culture)
	Asian and Asian American (includes Pakistanis, Indians, and Pacific Islanders)
	American Indians (includes Alaskans)

4. Check each block for any disability that you have been diagnosed for (in the past as well as currently):

	Developmental Disability (excludes Learning Disability and Traumatic Brain Injury)
	Learning Disability
	Attention Deficit Disorder
	Emotional Impairment
	Severe and Persistent (Chronic) Mental Illness (e.g., Bi-Polar, Schizophrenia)
	Traumatic Brain Injury
	Chronic Health Condition (e.g., Asthma, Diabetes)
	Physical Disability (includes sight and/or communication related disabilities)
	Other (please identify):

5. Check each block for any disability that a family member has been diagnosed for (in the past as well as currently). Family members include persons living as well as deceased who are/were defined as your partner (spouse, living together romantic partner), child, parent, and/or sibling:

	Developmental Disability (excludes Learning Disability and Traumatic Brain Injury)
	Learning Disability
	Attention Deficit Disorder
	Emotional Impairment
	Severe and Persistent (Chronic) Mental Illness (e.g., Bi-Polar, Schizophrenia)
	Traumatic Brain Injury
	Chronic Health Condition (e.g., Asthma, Diabetes)
	Physical Disability (includes sight and/or communication related disabilities)
	Other (please identify):

V. PROFESSIONAL CHARACTERISTICS

This section inquires as to the professional aspects of yourself in relationship to your employment with this organization, in the field of developmental disabilities as well as human services, and your education and relevant professional training. Also, please print or write legibly.

1. Taken from the current organizational chart, what is the title of your current job position in this organization:

2. In two or three sentences, briefly describe your role and key functions in this current job position:

3. Is you current job position considered a direct or indirect role (e.g., direct would include such positions as Supports Coordinator, Client Services Manager, Case Manager, Residential Staff, Day Program Staff, Job Coach or any other job position that require extensive direct contact and/or primary responsibility with people with developmental disabilities. Indirect typically speaks to administrative, management, and/or leadership positions):

Direct	Indirect

4. If you responded that you work in a direct role with people with mental retardation, describe the disability characteristics in percentages for the persons who you most closely work with (if you indicated your role as indirect, skip this question)

Disability	Percentage
Profound	
Severe	
Mild	
Moderate	

5. How long have you been in this current job position (if less than one month, enter "0" in both the years and months column):

Years	Months

6. How long have you been employed with this organization (if less than one month, enter "0" in both the years and months column):

Years	Months

7. How long have you been employed working with people with developmental disabilities (if less than one month, enter "0" in both the years and months column):

Years	Months

8. Excluding the time you have been employed working with people with developmental disabilities, how long have you been employed working in the human services field (if less than one month, enter "0" in both the years and months column):

Years	Months

9. Identify and briefly describe (two to three sentences for each) former positions you have been employed working with people with developmental disabilities:

Position Title	Direct Or Indirect	Brief Description

10. Excluding former positions you have been employed working with people with developmental disabilities, identify and briefly describe (two to three sentences for each) former positions you have been employed working in the human services field:

Position Title	Direct Or Indirect	Brief Description

11. Identify college degree completion (Major speaks to psychology, social work, public policy, human services, mental health, as examples. Designations speaks to AA, AS, BA, BS, BSW, BSN, MSW, MPA, Ph.D., Ed.D., J.D., as examples):

Degree	Major/Designation	Month/Year Completed
Associates		
Bachelors		
Bachelors		
Masters		
Masters		
Doctorate		
Other (Identify)		

12. In the past two years, have you had any formal training in the concept of self-determination (formal training is defined as a technical and/or substantive training in this specific area that was a planned event, conducted by an expert in the area, and was at least four hours in duration):

Yes	No

13. In the past two years, have you had any formal training in the concept of person-centered planning (formal training is defined as a technical and/or substantive training in this specific area that was a planned event, conducted by an expert in the area, and was at least four hours in duration):

Yes	No

14. In the past two years, have you had any formal training in the concept of community inclusion (formal training is defined as a technical and/or substantive training in this specific area that was a planned event, conducted by an expert in the area, and was at least four hours in duration):

Yes	No

15. In the past two years, excluding any formal training that you have had in self-determination, person-centered planning, and community inclusion, identify and briefly describe (two to three sentences) any formal training you have received related specifically to working with people with developmental disabilities (each formal training is defined as a technical and/or substantive training related to working with people with developmental disabilities, as individuals as well as

pertaining to systems, that was a planned event, conducted by an expert in the area, and was at least four hours in duration):

Training Topic	Description

Okay, you're done! Please give the Researcher your completed survey and take a well-deserved break before we get started with the focus groups.

Thank you :-)

VI. CODING (FOR COMPLETION BY THE RESEARCHER)

Organization Code #	Subject Code #

APPENDIX E

FOCUS GROUP ITEMS

1. How do you define self-determination for people with developmental disabilities?

2. What are the essential elements of self-determination practices for people with developmental disabilities?

3. What are the key ethical challenges evident in the application of self-determination practices?

4. What are the key barriers to the application of self-determination practices?

5. What are the key opportunities in the application of self-determination practices?

6. How do you define community inclusion for people with developmental disabilities?

7. What are some key community-inclusive outcomes?

8. What are the key ethical challenges evident in the pursuit of community-inclusive outcomes?

9. What are the key barriers in the pursuit of community-inclusive outcomes?

10. What are the key opportunities in pursuing community-inclusive outcomes?

APPENDIX F

THANK YOU LETTER

Richard James Visingardi, MSW, MPA
6225 Rosedale Road
Lansing, Michigan 48911
517-394-1352

[Date]

[Name of CEO]
[Name of Agency]
[Agency Address]

Dear [Name of CEO]:

I would like to take this opportunity to thank you and your organization for participating in my dissertation effort. I know how busy folks in the field are and you were all so gracious to take time out to provide me with valued information for my research. The desire to be a leader in promoting consumer citizenship, as evident in your involvement in the self-determination initiative, is amplified through your willingness to systematically examine what is learned along the way. I very much appreciate your allowing me to be a part of this process.

I have completed the data collection phase of this research effort. The remainder of this month will find me compiling and organizing the data and information in preparation for developing the findings and analysis. There is some outstanding information relative to the content analysis portion of my research (e.g., consumer support plans); however, I anticipate that organizations will have this information to me by month's end. Additionally, after I have completed the content analysis, I may be in contact with you to inquire about some minor additional targeted document resources (e.g., specific agency policy).

I hope to have the findings and analysis together in draft by mid-to-late January. As I stated, prior to putting this into final, I would extend an opportunity to review it with my sites to gather and consider their input. I will be in contact with you in early January to see if you would like to take me up on this option. If you elect to do so, I would be looking at an approximate two hour block of time sometime in late January. At your discretion, you may have any or all of the participants in this research effort attend this session.

As I had promised, I have also attached a copy of the first chapter of my dissertation (Review of Literature). Please note that this is considered a draft and will not be in final until after my defense. I will also provide you with a copy of my dissertation after it has been completed and approved as final.

Once again, I thank you and the members of your organization for inviting me in to pursue my learning in this area of supporting people with developmental disabilities. I also wish you the best in this holiday season as we look into all that awaits us in this fast approaching new millennium.

Sincerely,

Richard J. Visingardi, MSW, MPA
Doctoral Candidate
Michigan State University
College of Social Science
School of Social Work
Department of Political Science

APPENDIX G

RESEARCH CONTRIBUTORS BIOGRAPHICAL OVERVIEW

Technical Editor (Tammy Quillan): Ms. Quillan was responsible for editing and coordinating the dissertation through draft stages and ultimately into publication. Tammy holds a Bachelors degree in Business Administration and has had extensive experience as an Administrative Assistant for a CEO of a public county community mental health system and as a support staff in a legal firm.

Content Editor (Glenn Stanton): Mr. Stanton was responsible for completing a review of content of the final draft of the body of the dissertation. Glenn holds a Masters degree in Ecological Psychology and has just under twenty years of experience in state and local public mental health systems in the areas of quality improvement and program evaluation and has served in executive and upper management leadership roles.

Statistics Consultant (Shirley Ballard): Ms. Ballard was responsible for working with the researcher in analyzing the quantitative data collected from the survey component of this research effort. Shirley holds a Masters degree in Counseling Psychology and is currently an independent consultant and has had extensive experience as a research associate and evaluator with a both a public and private state health organization.

Research Assistant (Jeff Fudesco): Mr. Fudesco was responsible for serving as the second analyst for the content analysis component of this research effort. Jeff holds a Bachelors degree in Philosophy, is currently working on a Masters degree in Social Work and has a background working with people with developmental disabilities as an instructor and direct care staff.

Focus Group Co-Facilitator (Jeralyn Lowe): Ms. Lowe was responsible for co-facilitating the focus group component of this research effort. Jeralyn holds a Masters degree in Human Education and is most recently retired from long time employment with a state public welfare organization which included over seventeen years as a county welfare director.

APPENDIX H

UNIVERSITY APPROVAL

MICHIGAN STATE
UNIVERSITY

November 1, 1999

TO: Paul FREDDOLINO
254 Baker Hall

RE: IRB# **99-621** CATEGORY: 1-C,E
APPROVAL DATE: October 29, 1999

TITLE: THE INFLUENCE OF ORGANIZATIONS ON THE PRACTICE OF SELF-DETERMINATION AND THE PURSUIT OF COMMUNITY INCLUSIVE OUTCOMES FOR PEOPLE WITH MENTAL RETARDATION

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the **UCRIHS approved this project.**

RENEWALS: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Projects continuing beyond one year must be renewed with the green renewal form. A maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for a complete review.
REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.
PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify UCRIHS promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects or 2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at 517 355-2180 or via email: UCRIHS@pilot.msu.edu. Please note that all UCRIHS forms are located on the web: http://www.msu.edu/unit/vprgs/UCRIHS/

Sincerely,

David E. Wright, Ph.D.
DEW: bd
cc: Rich Visingardi

OFFICE OF
RESEARCH AND GRADUATE STUDIES
University Committee on Research Involving Human Subjects
Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046
517/355-2180
FAX 517/353-2976
Web www.msu.edu/user/ucrihs
E-Mail ucrihs@msu.edu

The Michigan State University IDEA is institutional Diversity Excellence in Action
MSU is an affirmative-action equal opportunity institution

APPENDIX I

FOCUS GROUP SUMMARY TABLES

Table I1

Organization A: Self-Determination- Defined and Essential Elements

Direct Quadrant	Indirect Quadrant
Defined	
Having choice, control, and direction over all aspects of their lives (e.g., money, friends, resources, where to live, who helps them) and receiving assistance from others in areas they have difficulty. Giving back to, being part of, and being recognized as a member of the community and being responsible for actions (e.g., if quit job, assume the consequences).	Choice, power, and control over where to live, social activities, funds, support services and development of abilities and knowledge of options and becoming independent as own person and engaging with the community. We used to decide, now they decide.
Essential Elements	
Movement from external control over people to internal control and learning about options, opportunities, and potential experiences and continuously supporting choices while the individual is continuously evaluating what is going on in their life and what can happen.	Education (client, parents, school, community) and experience (client) so can be accepted in the community, see what is in the community and trying out options as developed through PCP process of identifying wants and desires.

Table I1 (cont'd).

Direct Quadrant	Indirect Quadrant
Essential Elements	
Development of natural resource secured and self-esteem fulfilled relationships and movement of funds from programs to individuals.	Control of funds and individualized PCP-driven budget.

Table I2

Organization A: Self-Determination- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Health and safety considerations; however, may become clouded with the imposition of differing personal and/or organizational values and standards rather than the context of law and real concerns regarding the safety of others being applied as key guides. Mediating guardians who overstep their legal authority.	Health, safety issues, and behaviors (e.g., something may be desired but is not acceptable as it may be harmful to their health, choice may not reflect a good use of public funds) as with independent living comes greater risks and rights and responsibilities to be made know (as well as the consequences of actions). Overbearing family/public guardians advocating for segregated settings with professionals attempting to work through what the person can/should do and what the guardian says they can/should do.
Barriers	
Families and guardians are more restrictive resulting from historical context of "mixed message" and difficulty in connecting people to a community concerned about risks and liabilities and not treating them in the same manner as other citizens (e.g., range from police taking no action against people with disabilities in	Resource issues including financial (poverty, ability to pay rules, Medicaid prohibition of clients controlling funds, organizational liability concerns with client hiring and firing staff and assuming employer/co-employer role) and community characteristics (transportation, housing, employment limitations).

Table I2 (cont'd).

Direct Quadrant	Indirect Quadrant
	Barriers
matters where others would be potentially arrested to requests for persons to be placed back in institutions). Ability to move funds from programs to people and income-adverse Medicaid policies.	Parents and guardians have a difficult time "letting go" and difficulty in the organization shifting philosophy to personal choice.

Table I3

Organization A: Self-Determination- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Having what one wants in life (e.g., place to live, work, non-paid people who like you), building friendships, increased connections with the community and society in general, learning skills, and increased self-worth.	Increased satisfaction with more normal and fun life, economic advances by the community with inclusion of people with disabilities (e.g., contractor who develops housing) and, although a more demanding job, organization allowed to "think out of the box."
Reduction on system dependency and ultimate effect on the systems ability to serve more people.	Less dependency on the system will allow for increased people to be supported and served.

Table I4

Organization B: Self-Determination- Defined and Essential Elements

Direct Quadrant	Indirect Quadrant
Defined	
Being in control, freedom (exercising constitutional rights without compromise), becoming own person, opportunities for choice (e.g., where live, work, friends) and decision-making, expression of individuality, taking charge of life, selecting goals, living life like everyone else driven and based in PCP. Opportunities to learn, grow and blossom experience many different things while being supported and allowed to make mistakes.	Giving control to person (e.g., how money is spent, dreams, what they want to do with their life, where they want to live. Philosophy of empowerment is created through opportunities to make informed decisions (understanding the potential positive and negative consequences of decisions, understanding variety and options available in decision-making).
Essential Elements	
"Having a life" in making personal choices and taking control (e.g., making own decisions, options to choose from, not directed by regulatory forces, budget and support resources) while developing natural circles of supports and gaining exposure and taking responsibility for self in the community.	Inclusion of all financial resources (agency, income, food stamps, Home Help) as their personal budget with "dreaming" of what they want their life to be about as the step prior to developing a support budget. Knowledge of resources (financial as well as human--family, neighbors, colleges and others who want to be involved).

Table I4 (cont'd).

Direct Quadrant	Indirect Quadrant
Essential Elements	
Training and education for clients and staff (e.g., letting go and letting clients make decisions, teaching clients what they can do working from their strengths, obligations as a contributor in the community).	

Table I5

Organization B: Self-Determination- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Health and safety (e.g., balancing opportunities and risks, community ethics as related to safety of others) and organization learning to "let go" (e.g., conflicts and points of agreement regarding the "community appropriateness" and manner of supporting people with severe health issues). Determining who is actually influencing choices (e.g., concerns regarding discriminatory actions, adverse effect of limitations with both adequate natural supports as well as inadequate natural supports, interpretations by persons constantly trying to figure out what clients want).	Risk associated with decision-making (ranging from simpler choices such as daily eating habits to more complex issues such as choice to live in a dangerous area), allowing dignity of risk (allowing someone to make bad choices) while knowing that clients are vulnerable (resulting from being sheltered) of being influenced by others making decisions or imposing values. Liability concerns of the organization.
Barriers	
Community and support staff awareness, perceptions and diversity (e.g., variations in social class and ethnicity between direct support staff and clients, needing to infuse clients into the community to build sensitivity).	Resistance to change (e.g., parents--particularly as related to historical context; professionals--job security, code of ethics and "I'm the expert"; community--general lack of education; providers--loss of control, particularly as related to finances).

Table I5 (cont'd).

Direct Quadrant	Indirect Quadrant
Barriers	
Resistance to change (community, professionals, family, clients, families particularly as related to historical context of "mixed messages") and implications of provider community that has made a living operating programs for clients).	Dismantling old system financed around group-based program arrangements to move to individualized support financing.

Table I6

Organization B: Self-Determination- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Increased respect and dignity by professionals resulting from the client making life decisions which also lends to more enriched and meaningful contact between clients and support staff. Client is a better person to be around (includes a reduction in negative behaviors) as they are getting what they want and feeling better about themselves.	Desegregating the community as clients become citizens which results in increased interdependency and includes clients serving as volunteers and also contributing to the economic health of the community. Organization benefits as self-determination practices "bleed" to other people being supported and served as well as diminished financial resource demands lend to more resources available for clients.

Table I7

Organization C: Self-Determination- Defined and Essential Elements

Direct Quadrant	Indirect Quadrant
Defined	
Through the dynamic (changes constantly with new experiences and opportunities) PCP process clients make dreams and choices about where they want to live, what they want to do and other routine and non-routine life decisions with a personal budget aligned to the PCP. Persons make choices, are provided options to make informed choice, and are allowed to make mistakes.	Process of normalizing one's life through making choices (and assuming responsibility for said choices) in determining one's life, social contacts, work, housing, schooling, selecting who provides supports and fulfilling personal dreams. Individualized budgets (movement of program-directed funds to individual directed).
Essential Elements	
Opportunity to understand how to make informed choices, freedom from former segregated based restrictions, and education to former "controllers" (caregivers, guardians, community) to "back off." Resource management responsibilities and understanding costs for options, choice, empowerment, and exploring options and ramifications.	Offer choices and teach how to make good choices (how to evaluate the potential positive and negative consequences, natural consequences). Creating individualized budgets, shifting control from programs to teams and individuals, involving more unpaid persons in the individual's life, and cultivating more support opportunities in the community through education of the community (guardians, family, employers, providers, support staff).

Table I8

Organization C: Self-Determination- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Health and safety balance (safety net at least restrictive level), ethics of others (professionals, advocates, families) and overprotection of guardians may adversely effect choices. Balance between honoring choices and acting as a prudent steward of tax dollars.	Health and safety concerns in allowing a balance with opportunities as individuals may be vulnerable (e.g., hiring a support staff who is a known perpetrator, 900 phone solicitations) and balancing freedom and protection while not imposing values. Professionals and providers acting altruistically in adversely effecting self-determination when really concerned about their own security (e.g., loss of income, job security).
Barriers	
Various myths held by community (fear), guardians, support staff, parents, community, and providers. Lack of natural supports in rural area (e.g., non-paid persons, transportation, housing) and paid support staff.	Public policy direction (as related to managed care) is short-term sighted and does not acknowledge long-term commitment needs of people with permanent disabilities. Community education so they will learn how to accept "those people" and move beyond their untrue concepts of how people with developmental disabilities function (court and guardianship issues a particular concern--very restrictive and don't believe in clients speaking for themselves).

Table I9

Organization C: Self-Determination- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Changes occurring with individuals resulting from fulfilled dreams and lives is positively influencing guardians, providers and community members (e.g., seeing people as individuals not disabled). Movement away from "paternal government" lends to decreased costs.	Reduction in costs to the system resulting from client decision-making and the involvement of more unpaid people and changing perspectives with regards to how tax dollars are spent (movement from spending on care to investing in the community--such as labor and the need for employees). Happiness, fulfillment and increased quality of life (e.g., employment leads to income which leads to more things to do) and change in public perceptions resulting from client inclusion in mainstream activities (e.g., buying groceries, going to the movies).

Table I10

Organization D: Self-Determination- Defined and Essential Elements

Direct Quadrant	Indirect Quadrant
Defined	
Life for clients should be no different than it is for anyone else as they should seek to bring happiness to their lives, control their destiny and future, and control their lives. Elimination of control from others and making their own decisions rather than others making them (and the limitations that go along with that).	Have great input into goals, dreams, where they live, lifestyles, socialization and emotional needs. Clients get to make life decisions like everyone else within their resources, abilities and belief systems.
Essential Elements	
PCP (comprised of family, friends, and community members) getting together to identify things to happen (things in their life) and reflecting the clients comfort in making choices with supports contributing to their comfort level. Identification of options, variety, and different ways to get things done for making choices (client lack of life experience necessitates), elimination of all barriers and notions of barriers, and explaining potential consequences and responsibilities that go along with choices.	Funds to purchase supports and take part in activities. Development of natural supports through community activities (meeting people when they go to church) with said natural supports helping clients achieve goals.

Table I11

Organization D: Self-Determination- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Physical safety to prevent injuries and sense of responsibility in making decisions. Limitations relative to "I get anything I want," disagreement with guardians and family (and who is making choices), parameters around the use of public funds, and professionals' obligation to report some concerns (e.g., client who is a parent and exhibiting unsafe parenting).	Health and safety issues such as wanting to ride a horse but unable to do so, wanting to live in housing that is unsafe, hiring support staff that may not be qualified or are suspect, and general vulnerability that comes with a lack of life experiences. Strong personalities of a relative or support staff that could lend to supporting their own decisions rather than the clients and support staff who could have conflicting interests (financial stake).
Barriers	
Public opinion (ignorance, bias, fear, intolerance, stereotyping), control issues (parents, guardians, siblings, spouse, support staff), and the emergence of new "caregivers" when other caregivers are relinquished or give up this role. Inexperience and limited experiences of clients.	Community acceptance issues resulting from stigma, professionals and "it ain't gonna' happen," family with perceived notions of limitations, and general feelings of comfort by all in the status quo. Rules and limitations regarding funding and the general problem of poverty.

Table I12

Organization D: Self-Determination- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Become a citizen versus a consumer (productive member of the community, giving back to the community, not segregated) and becoming visible and spending time with people (non-paid) in the community. Enriching the person's life as they make choices just like anyone else.	Living like the rest of us, new experiences of freedom, personal growth resulting from choosing and trying things, learning from mistakes (can't make mistakes in group homes). Teaching client responsibilities, self-directing the development of goals, and self-respect gained from living on one's own.

Table I13

Organization A: Community Inclusion- Defined and Outcomes

Direct Quadrant	Indirect Quadrant
Defined	
Engaged in activities available to everyone in the community (working in the community rather than being in day programs, joining churches/groups/clubs, kids in school participating with kids with no disabilities—"mainstreaming"). Individualized options and choices.	Meeting others in the community (friends rather than reliance on support staff), joining clubs, and making new contacts (developing a natural support network). Normal life/normal activities (e.g., going to the Post Office, running errands).
Outcomes	
Self worth and changing (to positive) social attitudes. Rewarding to staff to see positive changes.	Increased community support, acceptance and recognition (in part as evidenced by increased inquiries from the community with a desire to become more informed), increase desire by families to learn (as evidenced by more questions), more discussion within the organization regarding self-determination, and more "real life" educational opportunities for clients (new classes on sex education and intimate relationships). People becoming their own guardians and more non-paid staff involved.

Table I14

Organization A: Community Inclusion- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Health and safety concerns (particularly as related to the safety of others) and as related to client-driven standards not other personal standards.	Blurring of boundaries (e.g., "when am I a friend and when am I a therapist?") as well as professionals' open mindedness regarding people with disabilities.
Boundaries in the relationship between professionals and clients (maintaining choice process within context so that professionals aren't "forced" to do things or become involved with things against their own values).	Determining who is and is not a good candidate for community inclusion (as related to vulnerability).
Barriers	
Resources (unpaid persons lacking money and/or time to become involved, transportation).	Rural nature of community (transportation, single dwelling housing, community activities shortages) and as hampered by public perception problems.
Increased vulnerability (perceived or real).	Medicaid financing limits as related to owning a home.

Table I15

Organization A: Community Inclusion- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Increased independence, skill-building (necessary to maneuver in the community), building relationships with ordinary community folks, improved self-esteem resulting from increased involvement with the community. Less reliance on system.	Education to educate community and change public perceptions, including in applied manner such as offered through school inclusion. More collaborative efforts where everyone in the community benefits (county-wide transportation, housing development initiatives).

Table I16

Organization B: Community Inclusion- Defined and Outcomes

Direct Quadrant	Indirect Quadrant
Defined	
Same life as anyone else in a community that is accessible and inviting into activities and is supported in needed areas.	Reciprocal role as the client is both giving and taking from the community (e.g., "working and paying taxes").
Reciprocal relationships (something expected of both parties--give and take).	Social inclusion (e.g., choosing church they wish to become involved with and developing relationships with members of said church).
Outcomes	
Accepting people as individuals, developing reciprocal relationships, recognizing them as contributors rather than takers, and making connections with people and places to achieve a better life.	Identification with community as evidenced in developing relationships with neighbors, coworkers, bosses and an increase in the number of people on circles.
Community as a better place to live (diversity and acceptance improves the community and lends to harmony).	Dissolving service delivery system (e.g., closing workshops).

Table I17

Organization B: Community Inclusion- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Maintaining segregated activities because choices are limited (resulting from client choices, funding limits, professional opinions, imposition of the values of others, public safety concerns). Inaccurate assumptions regarding natural supports (e.g., job expectation that paid support staff can be withdrawn and replaced with natural support of fellow employees).	Community safety issue (e.g., degree of latitude for clients with a history of behavior problems and the related potential for public safety concerns). As clients are more integrated into the community there are increased vulnerabilities and greater exposure to community prejudices.
Barriers	
Supporting a person when we take natural supports for granted and lack of resources (money, natural supports). Prejudices.	Economic issues and poverty (clients may dream things that seem reasonable but are unable to pursue said dreams due to a lack of financial resources). Community attitudes (fear and prejudice) and accessibility (accessibility issues, transportation).

Table I18

Organization B: Community Inclusion- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Growth for all (new people in the lives of clients, focus on new ways of doing things and using resource innovation is invigorating for support staff, community learning experience resulting from such practices as school inclusion). Increased client self-esteem.	Able to serve more people due to reduced costs and savings. Creating relationships and expanded job opportunities.

Table I19

Organization C: Community Inclusion- Defined and Outcomes

Direct Quadrant	Indirect Quadrant
Defined	
Normalized/integrated into the fabric of society (no more "us" and "them") in a community that accepts people for who they are and is supportive of all its members. Both clients and the community benefit (e.g., filling in employment needs, raising funds for charitable causes, one individual asserting ADA rights for accommodation and creating a response that benefits all persons with physical handicaps).	Working and living independently as opposed to day programs and group homes, attending social events in the community, having friends as opposed to paid professionals, and participating in routine community activities (e.g., voting, shopping, political process). Client worth based on strengths not weaknesses.
Outcomes	
Persons visible and accepted in an accessible community. Transportation available for all persons.	Both clients and community are more fulfilled through the development of non-segregated arrangements, visibility, and reciprocal relationships as clients are seen as productive citizens and social contributors (e.g., tax payers costs go down as clients get jobs and pay taxes, increased jobs in the community equates to increased economic prosperity of the community).

Table I19 (cont'd).

Direct Quadrant	Indirect Quadrant
	Outcomes
	Transportation services across the county and general community accessibility (e.g., accessible sidewalks) benefit the entire community.

Table I20

Organization C: Community Inclusion- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
Accommodations in the community and public values and social norms (e.g., different gender assisting in public toileting needs). Sexual relationships as well as intimate relationships in general.	Health and safety as related to individual and public safety (need a balance between public/community perspective with a consideration to what are best described as biases and prejudices and individuals ability). Concern that clients will be "cut loose" from supports in the name of community inclusion, but in reality as a result of managed care.
Barriers	
Resource limitations (transportation, housing, support services, selection of community/public guardians). Control and continuity issues ranging from providers not relinquishing control (based upon fears, overprotection, and assumption that mistakes will be made) to "mixed message" history as related to guardians and decision-making to schools not being particularly geared to necessary transitional planning.	Resource limitations (transportation, employment opportunities, human services, social opportunities) and time, money, and pool of volunteer limitations as related to developing non-paid supportive relationships (families also have limited time and money). Community attitudes ("those people") and guardians who won't relinquish control of client funds.

Table I21

Organization C: Community Inclusion- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Benefit to community (e.g., increased housing stock resulting from pursuits for clients equates to increased housing in the community), client as "giver and receiver," and community benefit concept as related to managed care. More well rounded life for the client as they are not dependent on group activities but rather become involved in individual activities that they choose.	Small town nature of community lends to clients "not getting lost" and peoples willingness to help each other. Higher visibility leads to increased acceptance.

Table I22

Organization D: Community Inclusion- Defined and Outcomes

Direct Quadrant	Indirect Quadrant
Defined	
Clients as having the same opportunities as everyone else to be a viable and active member of the community. To be accepted as a person as opposed to a disability stereotype and to have importance and meaning.	Participating in the community like everyone else in non-segregated activities (e.g., clubs, housing, recreation, Boards, employment). Access to businesses, using telephones, transportation, shopping, dinning out, etc.
Outcomes	
Life skills and growth resulting from experience, more appropriate behaviors, and expanded friendships. Giving back to community which, in turn, helps to educate the community and reduce ignorance, stereotypes, and contributes to the growth of others.	Greater public acceptance. Educating the public.

Table I23

Organization D: Community Inclusion- Ethics and Barriers

Direct Quadrant	Indirect Quadrant
Ethics	
"Safety net" concern as related to greater potential for vulnerability and victimization (e.g., 900 number telemarketers, simply meeting more and new people). Behaviors that come into question (e.g., wanting to drink but Doctor says no, sexually inappropriate actions that could lead to arrest).	Client decision-making regarding the use of financial resources (e.g., client decides to spend $11,000 on a car and nothing for support staff) and ethical conflicts (e.g., client decision to go to a "nudie" bar and organization's dilemma). Concern that clients may work harder in the community and could be taken advantage of (illegally) by employers and concern that the moral expectations for people with disabilities may be higher than what is placed on the rest of the members of the community).
Barriers	
Community stereotypes and perceptions (conservative community with more traditional stereotypes). Poverty in a relatively affluent community (e.g., lack of affordable housing).	Stigma of disability (e.g., concern with degree of intelligence). Lack of community accessibility (e.g., ramps, elevators).

Table I24

Organization D: Community Inclusion- Opportunities

Direct Quadrant	Indirect Quadrant
Opportunities	
Self-worth/positive self-image as well as increased community awareness and education leading to personal growth of community members. New friends, new experiences, live like everyone else in the community and opportunity to move out of poverty.	Economic advantages (more workers earning money, more money to be spent) and community exposure as contributing to a greater public perception and appreciation of differences as clients find their "niche" in the community. Client happiness, improved self-esteem, greater variety of stimuli and parents' satisfaction that their children live in their community.

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