Normalizing life experiences for individuals with developmental disabilities: a structural analysis of the process and an individualistic critique of the outcome

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Normalizing life experiences for individuals with developmental disabilities: A structural analysis of the process and an individualistic critique of the outcome

Eich, Roger John, Ph.D.

Iowa State University, 1994

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Normalizing life experiences for individuals with developmental disabilities:

A structural analysis of the process and an individualistic critique of the outcome

by

Roger John Eich

A Dissertation Submitted to the
Graduate Faculty in Partial Fulfillment of the
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1994

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CHAPTER ONE
INTRODUCTION

Historical accounts reveal that prior to the advent of the 1950s, it was socially acceptable to look upon and behave toward individuals with developmental disabilities as if these individuals were something less than fully human. With the passage of time, along with no small measure of devotion and long-suffering from untold numbers of social advocates, many members of the wider society eventually came to realize that this particular perspective was inaccurate and empirically unjustified. However, while such an antiquated point of view has been replaced by more enlightened frames of reference, often situations bear witness to the fact that social concern and empathy wax and wane.

Over the past eight years, while I worked as a direct-care provider, I observed first-hand that social barriers, both overt and covert, still exist between members of the "normal" society and those whom we designate as dependent upon our support. This is especially true if such support is required in meeting what we might consider as life's more mundane, ordinary challenges.

Sadly, I believe that it remains questionable if we, as a society, will ever arrive at a point in our history when such socially contrived partitions will be viewed as insignificant, superficial, and socially irrelevant. My feelings in this matter are predicated on the fact that American culture has always placed a high value on the very traits which individuals with developmental disabilities often lack, i.e., high degree of intelligence, self-reliance, competitiveness, and so forth. According to Wolfensberger
(1992), persons who can be placed into this type of category are often viewed as having little social value and are devalued as human entities. Persons who are so devalued are often treated in ways that indicate this social status. Traditionally, individuals with developmental disabilities have been offered low-quality housing, poor or no formal education, employment that offers low wages and few benefits, and second-class health care. Ultimately, Wolfensberger claims, such persons are labeled as social rejects, often ending up rejected, separated, and excluded from the wider society.

In America, there is a tendency to view entire groups of persons as if each member had the same core characteristics. This happens in the areas of race, ethnicity, gender, and sexual preference or lifestyle. It also happens to individuals with developmental disabilities. While persons certainly can be discriminated against on an individual level, there is a second, more devastating level at which prejudice and discrimination works its evil. According to Allport (1979), there is a tendency, especially in America, to devalue entire groups of individuals. The reason why this type of devaluation is more devastating is because it permits the members of the wider society to create and maintain socially constructed classes of people who are systematically discriminated against by individuals and a society's social structure.

However, having painted such a pessimistic picture, I must hasten to add that society is not without hope. At the present time, thousands of human service employees continue to forge ahead as direct-care providers whose work embodies those core attributes and qualities necessary to fulfill their service goals of full community integration for individuals with developmental disabilities. This is especially noticeable in the area of
residential services where modifications in service philosophies and treatment modalities play a vital role in continuing efforts to "normalize" individuals with developmental disabilities. However, progressing to the point where residential services could offer such care was not an easy endeavor and critics of such practices still abound. To understand how it is we have come to arrive at this point in residential care services and to grasp why resistance still exists requires a brief review of our cultural legacy.

**Historical Background**

During the past forty years, radical changes in elemental philosophies have acted to bring about significant changes in the human service field, especially as they relate to the care and treatment of individuals with developmental disabilities. To grasp and appreciate fully the importance of these changes, it is necessary to contemplate Western traditions and ideologies, along with revisiting a few historically significant social events.

According to Scheerenberger (1983), beginning in 787 A.D., both the Catholic Church and the State began sponsoring institutions which acted as surrogate keepers for those labeled as "mentally deficient." They did this by establishing and operating meager domiciles which attempted to offer a modicum of security and protection. However, most church- and state-sponsored institutions failed miserably at their tasks, and, as Scheerenberger points out, most children died under this model of care. In addition, towards the end of the Middle Ages, the Church's position changed with regard to how they looked upon these persons. While at first considering individuals with developmental disabilities as "innocents" and "gifts from God," its view changed to that of attributing their condition to the evil workings of the devil. Because of such spiritual
beliefs, parents of such children were reportedly filled with a mixture of grief and spiritual anxiety.

Neither the Inquisition, nor the Reformation offered little in the way of changing religious ideology towards these persons. For example, adding a new twist to an already dismal outlook toward the disabled, the rhetoric of the Inquisition held that if "mentally deficient" persons could not be helped by medicine, the disease was from the devil and their affliction rooted in witchcraft. Thus, it should come as no surprise that during the late 1500s, many developmentally disabled, especially women, were sent to the stake in order to "taste the flame" and be sent back from where they originated.

While treatment throughout Europe during the Middle-Ages and most of the Renaissance varied, one consistent factor in such treatment was that treatment was generally uncharitable and often took on a vicious, sadistic nature. For example, Scheerenberger (1986) points out that Hamburg, Germany, had its infamous "Idiot Cage," in which persons with developmental disabilities were confined and restricted to a life within a tower located in one of the city's walls. In contrast, in more rural territories, if such persons were found to be little or no trouble to themselves or others, they were allowed to roam the countryside, depending upon handouts and other forms of individual generosity from strangers to survive. It was also a common practice for rural communities to transfer responsibility for the care of these people by carting them off during the early hours of morning and unloading them within the confines of a neighboring village.
Scheerenberger also stated that professionals, members of royalty, and even high-ranking religious personages, including Pope Leo X, sought to include in their social circles a few "imbecile dwarfs" for amusement and other purposes. Sadly, with no one to act as a protective advocate, these social oddities often fell victim to pranks and cruel jokes often encouraged and dispensed directly by those who acted as care-providers.

England, too, had its methods for dealing with its disabled citizens. For example, in 1377 those labeled as "mentally retarded" were transferred from older, large institutions to Bethlem Hospital. Shortly thereafter, Scheerenberger (1976; 1983) reported that this new institution of care was given the title "Bedlam," and deservedly so. For, as the author points out, "...an inventory in 1398 revealed four pairs of manacles, eleven chains of irons, six locks and keys, and two stocks...for twenty patients!" (pg. 32). Those found to possess a less violent nature were allowed to roam the streets where they eked out a living begging on street corners.

The end of the Renaissance did bring about new ways of contemplating humanity and its surrounding environments. According to Patton et al. (1990), this included "...thinking [that] encouraged a philosophy of humanism, principally concerned with people's worth as human beings and with their freedom to develop to a maximum level" (pg. 6). However, it was not until the late 1600s that more holistic services for the disabled began to be developed, including services which provided substantially refined residential care.

Early attempts at providing residential care were more like efforts at warehousing society's refuse. These early human "experiments" often failed miserably, wracking
havoc and death on a substantial scale. For example, the death rates for children placed in state-sponsored or private institutions would be considered stunningly high and totally unacceptable by today's standards of care. According to Scheerenberger (1983), of the 2,000 children placed in Paris' Foundlings Hospital in 1670, 1,500 died within three months. The situation in that institution remained the same for over one hundred years. For example, of the 31,951 infants placed in the care of workers at the Foundling Asylum from 1771 through 1777, only 20 percent (6,391) survived the first year of services. Even more shocking was an example produced between 1775 and 1796 in Dublin, Ireland. Here it was reported that of the 10,272 children admitted to the Dublin Foundling Hospital only 45 survived the services provided them over those 21 years; a mortality rate of 99.6 percent. This pathetic beginning to much needed services was due, in part, to social ignorance and several myths which surrounded individuals with developmental disabilities.

Scheerenberger (1983; 1986) points out that members of the wider European society, including those responsible for establishing services, held fast to many erroneous attitudes and opinions about those they wished to serve. For example, it was widely believed that these people were untrainable, their medical conditions were incurable, that the disabled were impervious to cold, heat, pain, hunger, and, that if left to their own devices, they would become little more than beings controlled by their most basic drives, e.g., sexual drives, etc. Yet, in America, as in Europe, even as such obvious failures were taking place, some positive changes were fostered by the work of a few individuals.
According to Meyers and Blacher (1987), Dorothy Dix, an ardent campaigner for the rights of individuals with developmental disabilities, provided the first analytical examination of the plight of institutionalized individuals to the Massachusetts legislature. She reported finding the quality of care received by "idiots and the insane" wholly lacking and in need of revolutionary thinking. According to Patton et al. (1990), Dorothy Dix, "....was able to focus much attention on those whom she called suffering humanity" (pg. 10).

Samuel Howe was another important figure who played a direct role in the fusion of changing attitudes and actions aimed at improving the lives of those persons who struggled with developmental disabilities. Howe's biggest contribution was his advocacy for the view that members of the wider society had an obligation to educate and train those society labeled as disabled. He was successful in receiving state funding from the Massachusetts legislature for the purpose of establishing the state's first public school for training individuals with developmental disabilities. Unfortunately, not all state budgets could afford to follow Howe's revolutionary notions. In addition, during the mid- to late-1800s, what appeared to be shifts toward positive social change in regard to human service philosophies began to reverted back to earlier belief patterns.

According to Meyers and Blacher (1987), many schools were forced to keep their "incurables" and not integrate them, as planned, into the community. During this time, many advocates believed that it was crucial to protect and safeguard these individuals from members of wider society who were perceived as dangerously misguided by ideologies which spawned demands for a return to complete segregation. Some of the
reasons for why members of the wider society often felt like this included: a) an increased acceptance and adherence to the tenants of Social Darwinism and its accompanying conviction of the "survival of the fittest," b) ever more constricted state budgets and a growing reluctance to spend money on what were considered to be untested, even unnecessary, social programs, and c) the fear of genetic spoiling by allowing "bad genes" to be mixed in the wider, normal gene pool.

This last concern gave birth to the Eugenics Movement which called for eugenic segregation policies. Members of this movement lobbied state lawmakers, pressuring them to create and adopt involuntary sterilization laws directed toward anyone who might be considered genetically suspect. Those who fell under this law included, but was not limited to, convicted felons, sex offenders, vagrants, imbeciles, and women of ill repute. According to Macklin and Gaylin (1981), eugenicists used a two-fold justification for their demands. First, if such action was not subscribed to, American society would be flooded with groups of "sub-human" persons who would eventually be in conflict with members of the so-called normal population over what was perceived to be limited resources. Since these persons were devalued in so many other ways, it was not difficult to see how they might have been viewed as somehow less deserving of their "fair share" of society's material rewards. Second, and as during earlier times, those advocating such a radical position believed that persons with developmental disabilities were impervious to pain and any other forms of suffering that normal people may experience. It was in this fashion that many in American society practiced what can only be referred to as wide-scale dehumanization.
Thus, according to Taylor and Bell (1984), in order to protect the wider society from what it considered the danger of having suspect genes mixing in with the normal gene pool, many states passed legislation which mandated the involuntary sterilization of many "social undesirables," including what these authors referred to as "the menace of the feebleminded." Clearly, what had been a benevolent social outlook around the turn of the century had suddenly turned into a malicious reaction to what was then looked upon as a formidable and threatening adversary. While involuntary sterilization laws were not adopted by all states, Trombley (1988), pointed out that it was not until the mid-1960s that many states formally removed such statutes from their law books and officially disbanded their eugenics boards.

From the early 1900s through the 1950s, services for individuals with developmental disabilities changed little. Basic services did improve in small ways, as did the manner in which professionals opt to consider those labeled disabled. According to Patton et al. (1990), President Roosevelt's New Deal philosophy provided the format in which to reconsider and reconceptualize the manner in which the wider society thought of those in need of public assistance. Indeed, President Roosevelt's Social Security Act of 1935 went far in not only changing public outlook on public assistance, but also furnished its members with new attitudes toward all groups that were needy. Roosevelt's leadership went far in demonstrating the need for Americans to adopt new social attitudes and responsibilities, and, slowly, new developments in institutional care took hold in America. While large numbers of individuals with developmental disabilities were
warehoused in large institutions, a growing international movement, spearheaded in Scandinavia, was steadily growing in popularity (Switzkey et al. 1988).

According to Nirje (1976), this new ideological movement emphasized the need for more humanistic approaches in treatment and service modalities. Specifically, it called for human service agencies to adopt and engage specific training programs which would help persons labeled as developmentally disabled live a more "normalized" lifestyle.

According to Landesman (1987), this new service philosophy, called "normalization," provided a comprehensive framework on which to hang significant changes in delivery system designs that already existed in America. Adherents to this position believed in the psychological and sociological principles of behaviorism, and, in particular, the idea that both environmental structures and the process of socialization played vital roles in determining subsequent, adaptive behaviors.

However, according to Braddock (1988), while this model appeared to receive widespread acceptance, it remained a philosophy shrouded in confusion which gave way to a wide variety of definitions. This confusion also acted to fuel the debate between proponents who viewed normalization as the wave of the future, and opponents who needed more assurance that these new, radical ideas were not somehow flawed. Thus, while ardent defenders of this new philosophy went about the business of trying to implement the principles of normalization in delivery systems, detractors adopted a more conservative view, desiring to apply these new principles slowly, in more measured fashions with much caution and foresight. Eventually, the opponents lost and by the late
1970s and into the 1980s, real options in residential services and training were made available to individual consumers and their families.

These changes were impressive, especially when just a few years before, parents and other legal guardians of individuals labeled as developmentally disabled were given two basic life-pattern options. One option was to have their dependents remain at home, while the other was to seek care from outside service providers. Often, those seeking outside assistance were forced to deal with large, impersonal bureaucracies and state-sponsored institutions. According to several authors, (e.g., Kanner, 1964; Scheerenberger, 1976, 1983; Krishef, 1983), neither option addressed goals for achieving personalized independence. For example, Strain (1982) found that parents often lacked the time, energy, educational skills, and the economic and emotional resources necessary to instruct their children in the area of personalized independence. In the rare event that parents were able to address these goals, there was concern over the utility of such endeavors, because individuals with developmental disabilities often had no place to apply these skills once trained.

On the other hand, institutions offered little more when it came to working toward independence. Scheerenberger (1976; 1983; and 1986), points out that these "people warehouses" were often underfunded, overcrowded, and employed by staff who were overworked and underpaid. Several historical accounts of the day-to-day operations in these larger institutions demonstrate how the services provided were void of nurturing qualities. For example, Ryan (1980) and Blatt (1981) offered members of the wider society a glimpse into the shocking environment of the large institution. What their
personal observations and depressingly graphic photojournalism confirmed was the fact that institutional conditions were often physically dangerous, emotionally unhealthy and socially repressive. Their reports bore witness to a variety of brutal practices which ranged from serious punishments like solitary confinement and traumatic physical abuse to less dangerous disciplinary actions such as having to go to bed early without receiving the evening meal.

As mentioned, the 1960s and 1970s, marked the introduction of a radically new service delivery design born in Sweden a decade earlier and referred to as "normalization." Briefly, normalization refers to the process of creating environments which are as near to normal as possible. It also enjoins individuals who are developmentally disabled to live, learn, work, and enjoy leisure activities in more normalized situations. Beginning in the 1960s, conditions began to improve markedly for all persons who were physically or mentally challenged with disabilities. In America, the movement toward reassessing society's outlook toward persons who were disabled was assisted by President Kennedy whose sister, Rosemary, had been diagnosed as mentally retarded. Because of President Kennedy's leadership in the area of disabilities, the decade is remembered for its emphasis on the recognition and establishment of legal, personal, and human rights, along with the passage of several public laws, especially in the area of education (e.g., see Fox, 1982; Bilken, 1985; Marozas and May, 1989; Patton et al. 1990).

Thus, this new delivery service model, coupled with timely political interests, new legislation, and demands for social change, brought forth a new epoch for human service
delivery system philosophies. Results included significant increases in funding that were specifically ear-marked for programs and organizations that opted to incorporate these new principles. In addition, changes in federal and state statutes were aimed at improving the general quality of life experience for individuals with mental disabilities. For example, public laws (P.L.) included P.L. 83-531, which provided federal money for research into mental retardation and related areas, P.L. 89-10, which focused attention on the needs of disadvantaged students, and P.L. 94-142, which mandated the education of all students with mental retardation.

Normalization

According to Wolfensberger (1980, 1983, 1984, 1985, 1991a), normalization has never been assigned a universal definition. Rather, it has been operationalized in many ways, depending upon the area of interest held by those wishing to employ the term. According to Birenbaum and Cohen (1985), for educators it meant providing educational options for handicapped children, especially those where handicapped and normal populations could associate. Thus, educational choices ranged from totally segregated settings to least-restrictive classroom environments in which disabled students were "mainstreamed."

To administrators of residential agencies it has meant that individuals with mental disabilities could more readily develop and refine their independent living skills, and, as they did, they required and demanded more challenging, normalizing life experiences. In this particular service sector, options for individual consumers have ranged from living in traditional 11-bed group homes and 5-bed waiver home environments with their more
structured, supervised situations, to more independent, less structured living environments such as those offered under a scattered site apartment living program.

From a more general, sociological viewpoint, the concept in question refers to the normalization of social arrangements, relationships, and role expectations which exist between the wider society and those categorized as developmentally disabled. According to Kurtz (1975), normalization awakens society to the challenge of providing individuals with mental disabilities diverse, "normalizing" opportunities in order to maximize their abilities. Perhaps most importantly, the model invites members of society to reflect upon the importance of individuality, and what Rowitz (1981) refers to as social control of this segment of society. By accepting this invitation, advocates hope that members of society will begin to recognize persons with developmental disabilities not as a homogeneous collective, but as individuals with a unique range of academic abilities, social skills, distinct economic circumstances, and particular emotional needs and desires. Through this newly acquired perspective, individuals with disabilities are to be offered the chance to grow and develop in as many areas and directions as their interests, capabilities, and potentials carry them.

Clearly, normalization has been established in service spheres as the preferred philosophy which currently informs professional practice. The literature is filled with articles on the subject. For example, issues and topics have included discussions of normalizing behavior in community-based environments (Bjaanes & Butler, 1974; Nihira & Nihira, 1975), satisfaction and activities in the community setting for the disabled (Scheerenberger & Felsenthal, 1977), comparisons of alternative institutions (Willer &
Intagliata, 1982), residential design characteristics (Janicki & Zigman, 1984), impact of housing guidelines on residents (Holburn, 1990), follow-up studies and attitude checks in regard to deinstitutionalization (Grimes & Vitello, 1990), as well as community adjustment (McGrew et al. 1992).

Additional evidence for the pervasive impact of the normalization movement can be found at the federal, state, and local levels where statutes have been enacted to help ensure that normalization becomes the "law of the land." For example, Patton et al. (1990) lists no less than thirteen Public Laws which cover areas ranging from mandated vocational training and public education to the establishment of human and personal rights. Several texts also offer insight into just how influential the normalization movement has been. For example, Meyerowitz (1971), Robinault (1978), Craft & Craft (1978; 1983), Monat (1982), Trombley (1988), and Whitman & Accardo (1990), make up a very small sample of the numerous authors who have published on the subjects of marriage and sexual behavior between persons with mental disabilities.

Other topics featured in books and articles include focuses on community services (Birenhaum and Cohen, 1985), life-enhancing activities for elderly mentally disabled (Beisgen, 1989), changing patterns in residential options (Kugel and Shearer, 1976), the meaning of life for the mentally disabled (Heshusius, 1981), the politics surrounding the disabled (Ryan, 1980), and topics on education (Foxx, 1982; Biklen, 1985). Such writings give rise to the increasing number of adults with disabilities who are demanding their right to a full and meaningful life; a life that includes a full array of civil rights that go beyond mere tokenism. Take, for example, just a few of the humanistic findings
highlighted by Heshusius (1981) on "the meaning of life" according to the mentally disabled.

Heshusius discovered that the developmentally disabled wanted the same things the so-called "normal" population desired; they just sought liberty and the pursuit of happiness. In particular, they reported wanting such things as to stay home alone, to go out by themselves, and to merely feel good about making their own decisions about how to spend their money. Heshusius reported that the disabled desired marriage and felt that with the passage of time, more would eventually marry. In addition, Heshusius found that her respondents held very responsible attitudes and opinions with respect to sexual behavior, often preferring to reserve the most intimate practices, like sexual intercourse, for marriage. Lastly, the disabled reported both broad inter- and intrapersonal understanding. For example, they recognized their disabilities and realized that it did limit and restrict them in some aspects of their lives. Finally, Heshusius reported that these individuals were keenly aware of the loneliness and depression that goes with the label "retarded."

In most human service agencies, there is a concerted push toward advocating independence for their consumers, both in the United States and abroad (Shearer, 1976; Taylor and Bell, 1984; Landesman and Vietze, 1987). Many residential agencies have implemented guidelines and offered training sessions for staff in order to stress rights and options which must be presented to their consumers. One term, "choice-ability" (Nicholas, 1990) refers to the process by which individuals with mental disabilities are allowed freedom of choice and the ability and opportunities to operate control over parts
of their lives, i.e., self-determination. A few decades ago, merely considering such an idea would have been viewed as dangerously ill-conceived or even morally despicable.

However, despite the strong influence of normalization as a philosophical basis for delivering human services, the transition from institutionalizing individuals with developmental disabilities to community-based living in least restrictive environments has not been without opposition. However, even in the face of opposition, there appears to be no indication that human service industries are about to reverse their course and return to the days when warehousing residents in depressingly impersonal institutions was the only option outside the home. It is toward these opposing forces that the focus now turns.

Disagreement Over Claims

Despite the many positive changes that normalization reportedly has brought about, not all interested parties, professional and lay-person alike, agree with the viability of the concept. Beginning in the late 1970s, and carrying over into the early 1980s, several voices were heralding a warning about misuse and over-utilization of the normalization service model. In the 1970s, Rhoades and Browning (1975) asked a simple, yet dramatic question: Normalization at what price? These authors believed that the human service community was simply caught up in a movement that would ultimately deny persons with mental disabilities their individualism. One of their greatest fears was that social isolation would result from the lack of opportunity to establish and maintain peer relationships with other mentally disabled individuals. Similarly, Fram (1978) expressed concern that carrying normalization too far would result in individuals not having the
right to be disabled, i.e., to be themselves. Fram felt that the disabled persons should neither be "hidden" from society, nor should they be refused the right to be "retarded."

Thorne (1975; 1979) also voiced concern about the overzealous spirit through which normalization was implemented. For Thorne, normalization simply cut "too wide a swath" when it came to its inclusiveness. In essence, Thorne believed that professionals had arrived at the point where they had forgotten that the disabled, in fact, were disabled and classified as such through "normative procedures," i.e., comparison to ordinary conditions. Some of the questions Thorne developed were interesting and involved wider society's decision-making process. For example, since human behavior is continuous and varies, who is to say what is "normal?" How much difference is necessary to be classified as "abnormal?" Who is responsible for making the determination? Ultimately, Thorne did conclude that normalization had some redeeming qualities. He found that while service industries had the "right ends" in mind, they employed the "wrong means."

Similarly, Aanes & Haagenson (1978) found that among teachers and other professionals, normalization, as a means, was very misunderstood and appeared to be a "dead-end street."

Payne (1976) went as far as to suggest that a "deinstitutionalization backlash" would develop as a result of parental dissatisfaction, and empirical evidence appears to support this hypothetical concern. For example, in examining the attitudes of parents of institutionalized individuals toward their deinstitutionalization, Meyer (1980) reported that an overwhelming majority of respondents preferred an institutionalized setting to that of a group home or apartment setting for their children. In addition, Willer et al. (1981)
reported that half of the parents they interviewed reported that the process of
deinstitutionalization was a "crisis event" for the family, i.e., severe emotional reactions
such as guilt and anxiety that impaired the functioning of any member of the family.
Families who had a family member deinstitutionalized often reported stress and anxiety
over what was perceived to be the transfer of their son or daughter from a safe and
secure environment, to one that had too many unknowns, giving parents cause for
concern for the child's safety, security, and future.

Finally, Spreat et al. (1987) reported that their national survey of parents who had
children in institutions found that their respondents were generally not accepting of the
idea of community placement. Earlier, Mesibov (1976) had expressed what many parents
were still thinking a decade later - mainly, that more attention needed to be placed on
alternatives to the normalization philosophy. Mesibov suggested that more focus needed
to be placed on the individual and the results of normalization, rather than focusing on
how well service industries were conforming to the demands of a new service philosophy,
i.e., focusing on measurable goals and outcomes. Thus, instead of showing too much
concern for the organization and its goals, Mesibov believed that alternatives which had
humanistic qualities, such as helping the disabled develop positive self-images and
focusing on individual development, were more ideal. For many individuals, the idea of
normalizing disabled consumers had run its course and it was time to move on towards a
more individual-focused delivery system philosophy.

Also standing in opposition to normalization was Eve Hendrix (1981) who castigated
the professional community in her article entitled, The Fallacies in the Concept of
Normalization. Hendrix offered a collection of personal observations of programming situations in which normalization, in her opinion, were taken too far, i.e., examples in which normalization and deinstitutionalization were simply too inclusive. For example, during one visit to a residential service program she reported finding handicapped clients, whose mental ages were around four to five, not at home involved in programming, but rather learning how to consume alcoholic beverages at one of the local bars. Such an event might cause some persons to question the rationale for developing and implementing that type of Individual Program Planning (IPP). In addition, Hendrix provided first-hand accounts of deinstitutionalized persons who desired to return to their former service programs because they felt they had no support system on which to depend. Hendrix's conclusions included the finding that persons interested in serving the needs of individuals with disabilities often overlooked the needs of the very persons they wish to serve. In essence, a few well-intentioned persons had simply assumed that what was good for most normal members of society must be good for all persons, no matter what the disability.

Hendrix cited several others who also questioned the utility of normalization. For example, she reported that Birenbaum and Re (1979) found no significant movement toward independence, even in groups followed for four years after beginning independent living programs in their communities. In addition, Rhoades and Browning (1975) found that individuals with mental disabilities were often labeled as deviant. Moreover, they found that people with mental disabilities tended to seek out and form social groups with similarly labeled individuals. In essence, they tended to self-segregate. This finding
supports the notion that the mentally disabled may lack necessary support systems within
the so called "normal" population. A rather invidious implication drawn from this is that
normalization may have more to do with making service providers, politicians, and other
advocates feel good about what they are attempting to do, than with truly normalizing
those under their care, i.e., there may be underlying, self-serving motivations. Likewise,
Raynes (1980) and Ellis et al. (1981) strongly suggested that functional ability and
common sense be emphasized and employed as criteria when contemplating service
strategy options and long-term benefits in normalizing persons with developmental
disabilities.

Thus, not only have doubts developed about whether or not persons should be
normalized, but also about whether or not there has been an honest willingness to fully
adopt and implement normalization in practice. Some writers even imply that many
agencies merely offered superficial changes, rather than an honest effort at true change.
For example, William T. McCord (1982) appeared pessimistic when it came to residential
service agencies converting normalization from a status of philosophical underpinning to a
practical service delivery system. While crediting human service agencies with adopting
this philosophical model as a basis for their delivery systems, McCord points out that
many agencies have only partially implemented normalization's basic tenets. The author
suggests two important reasons for the overall lack of appropriate implementation. First,
McCord cited the work of Flynn and Nitsch (1980) who pointed out that there was a
general lack of funding required to put into place and maintain new programs affiliated
with normalization. This consideration is also one of the major factors for setbacks in
new programming in the 1990s. McCord also discussed the reporting of Pieper and Cappuccilli (1980) who believed that a general lack of implementation was due to the difficulties in interpreting the goals associated with the service philosophy, i.e., too many definitions and interpretations of the concept.

Finally, Schwartz (1977) perhaps sounded the most thought-provoking warning of all. Her thoughts draw attention to a pervasive societal view that all human beings are not created equal, and that no amount of discourse can ever change nature’s immutable laws. Normalizing those who are challenged by developmental disabilities is merely operating from an idealism that is based upon philosophical ideas which act to neglect and negate what is widely accepted as knowledge about individual and group psychology. Schwartz believes that normalization actually places undue amounts of pressure and stress on the disabled person. In Schwartz’s words, the entire program of normalization, as conceived,

....has placed an undue burden upon the retardate's (sic) psychic structure by exposing him to constant and repeated frustrations of enormous magnitude in the everyday world, and that these external pressures are handled primarily by the pervasive use of primitive defense mechanism. The mechanisms ultimately do not protect the individual from pathological processes (pg. 39).

For Schwartz, normalization is only possible if the environments surrounding the individual are capable of offering support and security without making any undue demands on others or the individual with developmental disabilities. Further, the author believes that normalizing persons is only possible in a social environment in which the wider society is not alien and whose ideals are attainable. If not, she contends that
normalization will take place in an environment that offers loss, isolation, self-hatred, and denigration to those who are to be assisted and made more independent by it.

The issues and concerns surrounding both the concept of normalization and the idea of mainstreaming individuals with developmental disabilities into the wider society are complex, even for many professionals who work within human services. Ultimately, any debate over the utility and success of normalization must return to and focus on those individuals with developmental disabilities who receive services from human service agencies. Of particular interest is whether or not these individuals are well-served by service arrangements, or, as some suspect, are they being betrayed by those who claim to have their best interests in mind? I believe that the only means of establishing the truth of the matter is to examine closely some of the issues encompassing normalization from both an organizational perspective, and quality of life issues from the consumers' perspective. If normalization is a viable philosophy that has been successfully translated into a reliable delivery system, then consumers should report high levels of personal satisfaction in many facets of their lives. Essentially, what needs to be determined is the degree to which normalization has been successfully implemented by human service agencies, and how their consumers feel about themselves and the world which surrounds them.
CHAPTER TWO
FOCUS OF STUDY

When it comes to both the process of normalization and quality of life issues for consumers who receive residential services from human service agencies, the literature offers several critically important areas in which questions remain in need of definitive answers. For example, is normalization the right approach to follow in acclimating individuals with developmental disabilities to the structure and expectations held by wider society? Have residential service agencies really adopted normalization and implemented its principles, or have they merely exchanged one kind of institutional setting and social control for other forms? To what degree have, or have not, changes been implemented in residential service organizations? Is normalization too inclusive for the disabled and nondisabled alike, as Thorne insists and others suggest? What about quality of life and the process of normalization from a consumer's perspective? Do they, or should they, agree with how wider society has decided to manage their lives?

Sociological Research of Related Topics

Sociological research efforts into areas concerning individuals with developmental disabilities are not plentiful. Traditionally, research concerning members of this group has been undertaken by persons in disciplines such as education, special education, psychology, and social work, as well as by a host of human service professionals. Most sociological probes into areas concerning the disabled have been couched in terms of social deviance, often with an emphasis on the mentally ill, (e.g., Goffman, 1961, 1963;
Eitzen, 1988; Hess et al. 1993, Macionis, 1993). However, most sociological studies do possess an innate modicum of cross-over making them applicable to most of the social conditions and concerns affecting individual’s developmental disabilities. For example, consider the writings in deviancy and the impact of labeling and stigma (Becker, 1963; Dexter, 1964; Spitzer & Denzin, 1968), various social psychological interests like attitudes and attitude change (Trandis, 1971; Gottlieb, 1975; Etzioni & Richardson, 1975) attribution (Smith, 1982), as well as group dynamics (Brown, 1988; Forsyth 1990), to name just a few.

In addition, through the use of qualitative methods Goffman (1961) exposed what life was like for persons living within total institutions. The conditions, daily routines, social interactions, and role expectations attributed to contemporary institutional settings described in his writings are not far removed from the experiences of many individuals with developmental disabilities. Goffman (1963) also examined the impact of labeling upon those individuals in society who were either unable or not allowed to conform to societal norms. Through extensive usage of autobiographies and case studies, Goffman analyzed how those labeled deviant come to view themselves and their relationship to the so-called normals around them. My own experience informs me that the same is true for individuals with developmental disabilities.

The Need for Research

As a group, individuals with developmental disabilities have taken a "back seat" when it comes to widespread sociological research interests. Considering the substantial size and the diversity found in this segment of our population, it is somewhat surprising that
this is the case, giving the impression of an oversight. One possible reason for this is to suggest that as a group, sociologists, like so many others, have developed or succumbed to the pervasive and persuasive attitude of social indifference. After all, sociologists are certainly not beyond the influence of persistent social forces. I feel strongly that at least three reasons exist for taking more of an interest in the sociological analysis of individuals with developmental disabilities.

First, individuals with developmental disabilities constitute a rather significant, and diverse, group within our population. According to Patton et al. (1990), estimates about the prevalence of mental retardation place the numbers somewhere between one and three percent of our population, depending upon how it is defined and subsequently measured. Identification of individuals as "mentally retarded" occurs at an early age, most often through psychological and intelligence testing during their first few years in grade school. Even with a public classification system in place, it is a less-than-perfect strategy, and many persons who struggle with developmental disabilities are never officially classified as "disabled." In addition, due to modifications in the methods agencies and states use to classify persons for services, estimates of the prevalence of mental retardation are likely to remain on the conservative side, e.g., lower quality or life requirements.

One of the most popular methods of identifying individuals as "mentally retarded," is through intelligence testing. For example, the Wechsler Intelligence Scale (Wechsler, 1967 and 1974) suggests using a deviation score with a mean of 100 and a standard deviation of 15. Thus, in a normal distribution, an individual who scores less than two standard deviations from the mean (less than 70), may be classified as mentally retarded.
Of those who are so identified, current trends in classification indicate that approximately 60% are classified as mild (IQ testing of between 69 and 51), 32% as moderate (IQ testing of between 50 and 31), and 8% as severe and profound (IQ testing 30 and below).

A second reason for sociologists to become more involved in this area of study has to do with methodological concerns. Researchers have demonstrated that individuals with developmental disabilities understand much about their lives and the diverse environments in which they interact, including high-level, abstract conceptual notions. Even after considering all the potentially troublesome elements involved with using members of this group as respondents, there still appears to be an almost irresistible desire for social research strategists to become involved in the challenges of constructing reliable and valid quantitative and qualitative instruments. Involving these individuals in the research process would give credibility to this group and send a signal that as a discipline we value what these persons have to say.

Finally, engaging these individuals in methodological activities is necessary if we care to ever truly understand their opinions, attitudes, aspirations, frustrations, and needs. I believe that the most consequential article on the subject of inclusion was penned by Wolfensberger (1988) in which he draws attention to the fact that people who struggle with developmental disabilities have several qualities which make them viable sources for research. In the piece, Wolfensberger identifies no less than fifteen "assets" which can be attributed to a rather substantial portion of this population. Some of the most compelling arguments included the fact that these individuals: a) have several strong humanistic qualities, what he calls "heart qualities," b) have a genuine concern for things
being well in the world, c) demonstrate something close to what wider society might consider unconditional love, d) often act as peacemakers for others around them, and e) possess an unfettered enjoyment of life's simple pleasures. Wolfensberger also suggests that these individuals' rigid and marred ability to abstract allows them to remain focused and less confused when faced with intellectual argument and other forms of deception and disguise with which members of the normal population must often wrestle. Finally, he further suggested that such qualities make them more likely to respond to others with honesty and sincerity, i.e., that individuals with developmental disabilities may be more straightforward and less measured in their responses.

The third, and final, reason for evoking a sociological analysis has to do with sociologists' most basic calling, as well as touching on ethical and moral issues. By examining different aspects of the group's social life, sociologists will most assuredly add to the body of important scientific knowledge. For example, at the micro-level, research can enlighten the wider community on issues surrounding intra-group relationships, prejudice, power, status, social role valorization, and so forth. In addition, sociologists could offer a better understanding of how structural processes are used in order to construct and modify the object, social realities experienced by these individuals.

Further, researchers can offer defacto assistance to members of the wider society as they may be motivated to develop more humanistic attitudes and normative patterns of social behavior toward those who have been historically regarded as different. For example, with respect to these ethical and moral issues, new research could provide society with an opportunity to re-examine its past with all the limitations and restrictions
it has placed upon this group. It would offer society the chance to begin contemplating a
future for an untold number of humans in which socially liberating agendas might move
from discussion to social reality. In essence, sociological research would present
members of society with occasions to rethink and even restructure social realities and
relationships, a suggestive ideal first offered by C. Wright Mills (1959), who would
invite all social researchers to interact with the personal troubles of others by considering
and examining the social issues and forces surrounding and influencing them. Research
would provide sociologists with the opportunity to put into practice what they have been
taught. That is, to bring to the research arena a critical imagination which allows them
to ponder issues sociologically, ultimately integrating theory and methods into an area of
noble social substance.

For example, with the current emphasis on normalizing or "mainstreaming" members
of this group, and because of what that may mean in terms of inter- and intragroup
relations, I believe it is imperative that sociologists take a pro-active research role. They
can offer agencies assistance in evaluating their service systems, and by offering
suggestions for reforming policies and instituting meaningful change. In addition,
changes in delivery systems often result in radical departures from traditional normative
patterns. Since social change is often tied to social psychological interests like attitudes
and attitude change (Deaux et al. 1993), sociologists should be able to offer professionals
effective strategies for implementing the changes they earmark as high priority items.
Specific Research Interests for this Study

My study involved the evaluation of one of the largest residential service agencies located in a mid-western state. While the target agency (referred to hereafter as "the agency") provided many services to individuals with developmental disabilities, it was primarily involved in providing residential services to adults. While limited somewhat in number, studies focusing on various life-interests that pertain to individuals with developmental disabilities presented me with reference points on which to build. Texts and journal articles have paid tribute to topics ranging from Christianity and its historical reaction toward society's less fortunate (Sider, 1979), to classical pieces on such topics as litigation (Jarvis, 1971), volunteer organizations (Stanton, 1970), and challenges facing the human service industries (Dybwad, 1964).

More contemporary interests include works on issues like performing plastic surgery on children who show physical features attributable to mental retardation, (e.g., Down's Syndrome) (Marozas & May, 1988), movement towards a new form of euthanasia aimed at the disabled (Wolfensberger, 1988), to assessment of students (Reavis, 1990), and early educational intervention (Irons-Reavis, 1992). Other areas and issues more relevant to my own areas of research interests include quality of life (Schalock, 1990), normalization and community integration (Flynn and Nitsch, 1980), and quantitative and qualitative research methods and measurement tools (Antonak & Livneh, 1988; Gardner, 1992), as well as a wide variety of efforts in the area of community-living (e.g., Katz,

In order to accomplish my research goals, I decided that there was a need to focus on four distinct areas of research, including: a) the degree to which normalization was accepted and implemented by the target agency, b) the existence and impact of internal obstacles to the process of normalization, c) the existence and impact of external obstacles to the process of normalization, and d) quality of life as experienced and expressed by consumers. These areas are further broken down to provide background and highlight various concerns found in each area.

**Interests in Examining the Process of Normalization**

While most professionals understand what the concept of normalization encompasses, many fail to grasp that as a philosophical scheme it has three distinct levels of operationalization: the individual, the organizational, and the societal. According to Wolfensberger (1980), whenever the concept of normalization is examined it should be evaluated in terms of its implications at all three of these levels of social organization. The model that he provides has, with minor adjustments, a certain amount of utility in my own study. The scheme contains the following:

1) Individualistic Level - This level refers to the micro-level interaction that takes place between individuals with developmental disabilities and members of the normal, wider society. While not solely limited to specific interactions, most often this occurs with members of the residential service organization staff. At this level, emphasis is
placed on interactions that focus on similarities rather than differences. For example, interest is given to whether or not certain labels are attached, if persons are manipulated or managed, and if interaction "separates" or maintains a gap between those involved. Do those involved at this level demonstrate normalizing emotions, attitudes, and behaviors towards one another, e.g., love, kindness, attention to person, honesty, fairness, equality, and so forth? Or do those who work with the disabled operate under the assumption of a hierarchal "natural order" perspective?

2) Organizational Level - At this middle-range, or meso-level, the focus is on the relationships that exist between the individuals with developmental disabilities and the immediate social systems which surround them. For example, systems such as the family, church, commercial establishments, work environments, and the residential service organization fall within this category. Interests at this level include whether individuals are perceived as persons of value, or dehumanized by nondisabled individuals. The structural norms of organizations need to be examined in order to determine whether or not individuals with developmental disabilities live, work, and socialize within normalizing situations, with an emphasis placed on acceptance. For example, are the routines involving the consumers really normalizing, e.g., elements of their residential settings and programming, work environments, social and community lifestyles?

3) Societal Level - At this macro-level, the focus is on whether or not, or how far, persons with disabilities have been integrated into society at its broadest levels. This includes large-scale social structures like religious, economic, and governmental
institutions, as well as the federal, state, and local legal systems. The emphasis at this level is placed on social acceptance and tolerance, and research interests at this level have to do with the totality of inclusiveness in American culture. This includes examining whether or not, or to what degree, negative attitudes and stereotypes affect the over-all recognition of this group as full-fledged members of society. Specifically, interests lay in the degree to which individuals with developmental disabilities are truly integrated into the larger society, and to what degree this process is hindered or facilitated by the activities found at the other subordinate levels.

Thus, taking into account the multi-faceted, three-dimensional schema of the normalization concept that appears above, the following operational definition, as drawn from the work of Nirje (1976) is offered:

Normalization means sharing a normal rhythm of the day, with privacy, activities and mutual responsibilities; a normal rhythm of the week, with a home to live in; a school or work to go to, and leisure time with a modicum of social interaction; a normal rhythm of the year, with the changing modes and ways of life and of family and community customs as experienced in the different seasons of the year (pg. 231).

This definition clearly demonstrates that the emphasis is not on making individuals with disabilities "normal," but, rather it focuses on making their life conditions as "normal" as possible. However, it has been my experience that these important distinctions are often overlooked as these two interpretations become merged. In residential programs, I believe the confusion stems from the actual transformative processes involved in moving normalization from an ideology state to concrete forms of
services offered at the direct-care level. Workers can confuse the process of training and preparing individuals for more normalized lifestyles and environments with the actual ideal of normalization. In addition, the above definition is viewed as implicitly relative, allowing the person applying it to do so with the sense that it takes into account individual differences. These differences include things like degree of disability, individual economic factors, a person's changing social conditions, and so forth.

In my study, there was an obvious need to establishing the degree to which a single residential service agency, its employees, and their service activities adhered to the principles of normalization. In particular, I wanted to see if the agency and its employees had a clear understanding of what normalization means, and, further, how it was translated into official policies and staff activities. Doing these things allowed me to begin understanding whether or not normalization was truly an important goal for the agency, or if it was merely impression management rhetoric.

**Internal Obstacles to the Process of Normalization**

Discovering that an agency officially recognizes and accepts the principles of normalization is one thing, but ensuring that they are followed in the day-to-day operations can be quite another. Thus, it was important to discover just how effective the agency had been implementing normalization at the direct-care level and to discover if various internal obstacles to the normalization process were present. If they were present, I wanted to identify them and examine the extent to which they impeded the consumers' success in training and social opportunities. Specific internal obstacles
examined included a variety of attitudes held by staff, incidents of abuse, practices of excessive social control, and the physical layout of residential environments, including the presence and impact of house rules.

**Staff Attitudes as Internal Obstacles**

Farber (1968) stated that residential staff who serve the mentally retarded often take on very authoritarian-type personalities. Even as late as 1987, significant numbers of staff were found to hold custodial-like orientations which acted as obstacles to the normalization process (Emerson and Emerson, 1987). Because this almost always involves mind-sets and egos, it is only logical to hypothesize that such attitudes might lead to detrimental, interpersonal conflict between staff and consumers. The demands of the work environment also can lead to non-normalizing attitudes, much of it due to "worker burnout", a well-established, serious problem within this type of service industry (Maslach and Jackson, 1981; Pines et al. 1981). Edwards and Miltenberger (1991) described such patterns as "emotional overload" that leads to exhaustion that occurs when people become too involved and begin feeling overwhelmed by the emotional demands of working with disabled individuals. The problem of worker burnout can have a direct impact upon the amount and quality of interaction between staff and consumers, in particular the care and programming received, as well as the general quality of life experienced by consumers.

The importance of staff attitudes was examined by Hile and Walbran (1991) who found that attitudes and the type of staff involvement and interaction, including
socialization, task training, or leisure, played important roles when it came to agency success. Likewise, Pedler (1990) discovered that when staff insisted on bringing large-scale institutional attitudes toward clients into smaller community-based settings, the attitudes worked to reduce the amount of consumer community integration. Identification of obstacles to the process of normalization is a difficult matter to ascertain, especially when a portion of the study involves the idea of examining staff attitudes.

In the present study, the assumption behind the methods is that prejudices held by staff members may lead to an intention to take part in discriminatory behaviors. Such behaviors, in turn, may act to preclude the process of normalization. I felt that several factors in regard to attitudes might play a role in either fostering or blocking this process. These included such things as staff attitudes about their work, how staff view those under their care, and their feelings toward interaction with their consumers. In order to discover whether or not such obstacles were present within the agency's staff, I incorporated the Community Residence Personnel Opinion Scale (CRPOS; Jacobson, 1990), a multi-dimensional scale that is detailed in the next chapter. Sub-scales in the CRPOS include such items as staff irritability, feelings about equality, negative ward management, friendship, and verbalization.

Staff Attitudes Toward the Sexuality of Their Consumers

One of the most important rights humans enjoy is that of expressing their sexuality. This is one of the last frontiers in which societal taboos haunt individuals who have been labeled as developmentally disabled. Traditionally, attitudes toward the sexuality of these
individuals have changed little in comparison to more general attitudes about individuals with developmental disabilities. Since even nondisabled persons have a difficult time discussing and agreeing upon sexual matters (e.g., sex education in school, AIDS prevention, using condom commercials on television, and so forth), it only makes sense that society has an even more difficult time dealing with the sexuality of those classified as "mentally retarded." To many in the wider society, the disabled often are seen as incapable of understanding things like sex, pregnancy, birth control, and other sex-related topics and behaviors, and their attitudes reflect such sentiments.

For the most part, the topic has remained a rather uncomfortable subject, taking on an air of something more suitable for television talk shows in search of sensational topics to air or, at best, something that is best left in the hands of care-providers who have experience in dealing with such matters. Moving beyond staff attitudes and social structure for a moment, it would appear that residential environments play a central role in determining the extent of sexual freedom experienced by consumers. For example, consider, the structural design of the living quarters or the existence of formal or "informal" house rules and guidelines, and how they may impede access to the necessary privacy for having sex. Early studies linked increased homosexual activity among consumers to such structural factors. For example, in one study Ushew (1972) reported that 37% of mentally retarded subjects reported taking part in homosexual acts only while living in a group home environment where contact between the sexes was highly regulated and controlled.
Closer to the topic at hand, studies often report that caregivers' attitudes reflect ignorance and out-moded values and norms. For example, caregivers reportedly: a) discouraged dating, b) endorsed heavily chaperoned social activities, c) believed in punishing clients for taking part in sex acts, and d) felt that they could not leave clients alone for more than one hour since they would take part in sex acts (Craft, 1987).

Parents and legal guardians can also play a role in determining the sexual experience for their sons and daughters. Buscaglia (1983) pointed out that parents need to be patient and caring when it comes to counseling their handicapped children in the area of sex. Parental fears having to do with exploitation, experimentation, and irresponsible exploration must be balanced with the knowledge that one can successfully socialize their handicapped son or daughter with respect to sexual behavior. Those who wish to believe that intimacy is not important to individuals with developmental disabilities only fools themselves. It was also apparent from data collected during the consumer interview process that sexuality and related issues were principal concerns for respondents.

According to Geraghty (1979), there is a tendency for residential professionals to assume that they have some type of right to make the sexual desires and behaviors of their consumers their own business, even to the point of making decisions for them without having the courtesy to seek input from the consumer. Again, this ultimately leads to the serious problems of overprotecting and overcontrolling consumers. According to Craft (1987), survey data showed that,
...sexual frustration [in the disabled], contributed to a significant or major degree to most retarded people's problems of adjustment, the only forms of sexual release that received a majority endorsement were private masturbation, brief kissing in private or public and private petting. It was found that 31.2 percent [of residential staff] felt no sexual behavior, not even simple physical contact, was acceptable (Craft, pg. 87).

In looking towards the future, Craft concluded,

...in the future it may become even more important to ensure that nurses and care staff are given an adequate training on sexual behavior and ways of counselling the mentally handicapped (Craft, pg. 90).

How can staff begin to help the mentally handicapped achieve a coherent model of personal sexual behavior without the prerequisite of consistent reaction to the sensitive subject from superiors at all levels in the face of any situations and even the most adverse public comment (Craft, pg. 90)?

It is generally assumed that the principles of normalization recognize that individuals with developmental disabilities have a need and right to express themselves sexually. However, it has been my experience that many consumers are systematically denied the opportunity to develop and express themselves in this manner. According to Kempton (1991), it was not until the advent of the 1970s that the sexuality of individuals with developmental disabilities was not handled by denial and suppression. There still remains ample evidence to suggest that many members of the wider society, and even a significant number of human service providers, are uncomfortable about granting the developmentally disabled to the right to engage in sexual behavior. However, sex and individuals with developmental disabilities is a fact of life and it is important that staff recognize it. For example, with the arrival of Acquired Immune Deficiency Syndrome (AIDS), it has become paramount that good sex education is part of the training packaged
subscribed to by residential service agencies. Kempton, along with Trudel (1990), believes that specific training goals, guidelines, and adequate curricula have been developed and need to be employed.

However, somewhat surprising is the fact that many residential care facilities do not have a set of policies which provide staff members with guidance in this sensitive area. According to Chapman and Pitceathly (1985) and Brantlinger (1987), this is one of several reasons why there remains a general tendency among staff to adopt a "supervisory role," and, in turn, very conservative attitudes about the sexuality of their consumers. Such activity stands at odds with the tenets of normalization because it demonstrates that staff may maintain a double-standard about the sexuality of normal and "retarded" persons. They may feel that individuals with developmental disabilities cannot understand sex, that they do not have such drives or needs, or even that they cannot be trusted to act responsibly if allowed to explore their sexuality.

As individuals with developmental disabilities have continued to move from institutions to less restrictive residential environments, it is imperative that they receive normalizing training with regard to sexual expression. According to Valles (1982), even parents of deinstitutionalized individuals were in favor of such training, but were unsure of who actually should be given the authority to supervise such training. As early as the 1970s, many believed the responsibilities for such training should be located at the direct-care level in community residences for the developmentally disabled (e.g., Gupta and Singh, 1973; Kempton, 1977 and 1978; Jacobs, 1978; Hamre-Nietupski and Ford, 1981;
Therefore, if and when consumers develop an interest in sex, human service agencies should be ready to provide training and discussions about sex-related matters. In this way, staff members can help assure that their consumers develop healthy, positive outlooks on sex.

This is especially important if consumers hope to one day enter and live independently within their communities where socially acceptable behavior, including community-adaptive sexual expression, is mandated. In addition, the fact remains that unless properly educated and trained, individuals with developmental disabilities may remain at risk for exploitation and abuse, even at the hands of direct-care staff and other professionals. Thus, along with collecting data about general attitudes held by staff, I also wanted to collect data on staff attitudes towards the sexuality of individuals with developmental disabilities. In order to accomplish this, I employed Ellen Brantlinger's "Sexuality and the Mentally Retarded Attitude Inventory (SMRAI; Brantlinger, 1983).

The SMRAI was designed for research with groups where understanding staff attitudes and measuring staff attitude change are the key interests. In addition, the scale is often employed and useful in terms of initiating discussion on the sexuality of the disabled, as well as having utility when it came to organizational assessment in determining the need for in-service training on the subject of staff and their attitudes toward their consumers. The SMRAI allows the researcher to assign individual scores, often for the purpose of assigning individuals to either a conservative or liberal group, which are indicators of staff tolerance toward their consumers' sexual behavior.
According to Brantlinger (1983; 1987), a liberal score would indicate a respect for the human rights and needs of individuals with disabilities, non-stereotypic views of their sexuality, and a permissiveness in allowing and supporting their choice of sexual expression. A conservative score, on the other hand, may be an indication of intolerance and rejection when it comes to staff and the sexuality of their consumers. Staff with conservative attitudes may be viewed as potential obstacles toward normalization inasmuch as they may manipulate environments so as to preclude consumers from engaging in sexual expression.

**Consumer Abuse and Excessive Social Control**

A rather serious group of concerns when discussing obstacles to normalizing individuals with developmental disabilities includes those surrounding the issue of abuse and what I refer to as excessive, or surplus, social control. Individuals with developmental disabilities are psychologically and sociologically conditioned to view themselves as powerless in most social, economic, and political situations. The effects of having been labeled "mentally retarded" are well documented in various disciplines, ranging from psychology and sociology to special education and social work. Because of the physical and cognitive limitations found in the persons who are disabled, coupled with the fact that staff persons often look upon those under their care as the "they" in a "we-they" group situation, it is easy to see where manipulation and control are valid concerns.

Waxman (1991) argued that individuals with developmental disabilities need to be included as a "group at risk" in the Federal Hate Crime Statistics Act, which was
established to track hate crimes. She feels that violence and abuse perpetrated against those labeled disabled is often masqueraded as medical treatment, including psychosurgery and aversive or excessive behavior modification programming. Further, Sobsey and Doe (1991) found that abuse and assault were frequently repeated and chronic, often resulting in serious harm to the victims. Somewhat distressing was their finding that most of the abusive situations were not reported to welfare or law enforcement agencies. Finally, Tharinger et al. (1990) and Westcott (1991) also concluded that disabled persons were at increased risk for abuse and that new policy and research initiatives were required in this area. For example, Tharinger et al. (1990) reported finding that individuals with developmental disabilities were particularly vulnerable to sexual abuse and other forms of exploitation and were in need of intervention services. Reasons for such vulnerability included: a) dependence upon care-providers, b) relatively powerless position in society, c) emotional and social insecurities, and d) a lack of education with respect to recognizing and reporting abuse. Likewise, Hewitt (1987) remarked that a strong likelihood for abuse, especially sexual abuse, existed for individuals who were deinstitutionalized and living within their communities. Finally, Corin (1986) also reported that rates of abuse reported by care-providers were as high as 50%.

Obviously, residential situations in which abuse and excessive social control are common would act as serious obstacles to the normalizing process. While many may find it hard to believe that such practices might occur at all within an environment that is
suppose to be filled with loving, caring service providers, others do not. For example, Berkman (1986) pointed out that while most sexual abuse was committed by care-providers, it is committed in situations in which the victims are least likely to report such attacks due to fear of retribution. Thus, given the immense imbalance of power that exists between staff persons and the individuals they serve, it is important to see whether or not abuse and excessive social control are present at any level in the agency.

In my study, I thought it critically important to measure the prevalence of such activity by asking employees at all levels within the agency to indicate the frequency and types of abuse and excessive social control of which they were aware. For clarity, I asked staff to differentiate between physical, sexual, and emotional abuse reporting. If significant numbers of affirmative reports were uncovered, then one might logically conclude that where such abuse and control takes place, the process of normalization most assuredly would be impacted in negative fashions. In addition, I asked employees to provide specific examples of how they, or others whom they knew, exercised methods by which excessive social control was carried out.

Features of Residential Environments as Obstacles to Normalization

Finally, a brief spatial analysis was completed on a number of the agency's residences. The purpose for this was to establish whether or not the residences, themselves, were conducive to normalizing, "home-like' atmospheres. In addition, it is common knowledge among workers that house rules exist, both formal and informal. Thus, I felt it was paramount to attempt to discover whether or not rules of either kind
existed that might act to restrict and constrain consumers. This portion of the analysis took into account three different types of residential settings: traditional group homes, waiver homes, and apartment complexes.

Although I visited several individual apartments during the course of my study, they were not made part of this phase of my analysis due to the fact that most, if not all, apartments were found to meet the criteria for normalized housing. In order to standardize my data collection efforts in this area, I incorporated a modified version of the Characteristics of Physical Environment (CPE; Jacobson, 1990). This measure requires the observer to rate residences on 11 indicators of normalization, ranging from the outside appearance of the lawn and the residence's location to the amount of private space each consumer is provided.

Residential environment is important for several reasons. Baroff (1980), who examined size of residence and quality of care, found that the size of the residential setting made a difference. For example, smaller residences were reportedly more responsible to the needs of the consumers. In addition to size, Baroff found that the residence's location in the community made a significant difference with respect to access to various community experiences. The author concluded that these community experiences were vitally important to enhanced training in social, vocational, and recreational skills. Obviously, such experiences would be more difficult to provide if consumers lived in an isolated, large institution. In addition, it would be easier to have parental involvement if consumers were residing at smaller, community-based facilities.
Such interaction has been shown to be a very positive factor in most consumers' lives (Balla, 1976).

Additionally, Seltzer (1981) found that when residences were more normalized, there was increased training, increased opportunities to assume in-house tasks, more privacy and autonomy, clearer performance expectations, and increased access to resources. Similarly, Janicki and Zigman (1984) concluded that when residences were more normalizing in appearance, allowing for more physical integration within its neighborhood, it added to the consumers' ability to become more socially integrated. According to Burchard et al. (1991), differences in residential type were an important factor effecting various training strategies, as well as other features of normalization. According to these authors, residential settings provided different lifestyles with respect to independence, differing amounts and types of staff-consumer interaction, dissimilar normalizing opportunities, and distinct degrees of community integration. For example, consumers who lived in apartment settings reported the most normative lifestyles, showed greater personal independence and community integration, and reported high levels of lifestyle satisfaction.

In addition, other studies indicated that smaller, more integrated residential settings offered advantages such as enhanced individual dignity and community involvement (Bowd, 1989), placement satisfaction and increased independence and integration within the community (Burchard et al. 1991), and expanded development of new social contacts (Jones, 1986).
With respect to my study, even though many individuals with developmental disabilities live in more normalized surroundings, I am concerned that their physical environments, along with housing guidelines or "house rules," may encroach upon the process of normalization and upon consumers' personal and human rights. Spatial examination of residential facilities, coupled with content analysis of house rules, along with informal conversations with housing staff shed light upon questions in this area.

**External Obstacles to the Normalization Process**

At the time I prepared my study, I was aware of only a few potential situations in which external obstacles might work to block the agency's attempts to normalize its consumers. These included the fact that the agency was reliant upon outside funding sources, including federal, state, and county treasuries, as well as donations from local charities. It is a fact that whenever money is given, strings are attached, and, with respect to agencies that provide residential services, there may be limitations and restrictions on certain monies for specific programs. Also, there are other human service agencies which also work with the agency's consumers and whose objectives and goals must be taken into account. These include day program providers, employment agencies, employers, schools, and medical institutions. Each of these programs may have requests and guidelines of their own which impact the agency in ways that may not be functional when it comes to the agency's attempts at normalizing their consumers.

In addition to other human service programs, the agency must also contend with various external groups and individuals whose purpose is to advocate for consumers.
These normally include parents, legal guardians, and friends who all may insist on having requests fulfilled which may stand at odds with the agency’s preferences and procedures. These might include things like restricting access to social opportunities, applying travel restrictions, demanding different residential environments, or even holding up certain training objectives due to concerns over methods or goals.

Finally, the community in which the agency is located may act as an obstacle from time to time. This is especially true when it comes to locating new residences for different programs. Neighborhood citizens often become very concerned when they believe that some type of special group home is to come into their area. There have been serious attempts at blocking the leasing of properties by various human service agencies in the local area, not just those pertaining to the agency. In order to identify all of the different types and nature of any external obstacles, interviews were conducted with several of the agency’s higher-ranking, management-level employees at the agency.

Examining Quality of Life Issues

If normalization is the means to an ends when it comes to the most popular delivery service philosophy, then "quality of life" is the underpinning for the concept which I believe appropriately captures its end. It is almost taken for granted that if community-based residential and employment agencies provide individuals with developmental disabilities with effective services, then a high degree of quality of life will be an inevitable outcome (Heal & Chadsey-Rusch, 1985). However, given that persons with developmental disabilities have the ability to express their preferences for various service
alternatives, this is not necessarily an "inevitable outcome." In fact, as a direct-care provider for over seven years, it has been my experience that high degrees of quality of life often is a missing commodity that is discussed quite often and in different ways among consumers.

For example, I can recall several occasions in which consumers expressed boredom, loneliness, frustration, and anger over what they perceive as excessive restrictions and unrelenting pressures to accept the socially constructed boundaries of reality heaped upon them. One such incident took place at a consumer's apartment where I had been invited to dine. During the course of the meal, we discussed many topics and issues relevant to the person's quality of life. All appeared fine until the person broke into uncontrollable tears. After regaining composure, the person apologized and explained that our discussion made him think of how isolated and lonely his situation really was. The person talked about his limited contact with his family and friends, the fact that he received very limited support and contact from service agency representatives, and had very restricted access to the community due to limited access to the local transportation system. So, how should researchers approach this complex, very individualistic concept in a research setting? The literature offers some sound options.

Schalock et al. (1989) presents a multi-dimensional construction of quality of life based on principal component factor analysis. Their solution contained three factors, including an "environmental control" factor containing 15 variables, a "community involvement" factor containing six variables, and a "social relations" factor containing
seven variables. In addition, Heal and Chadsey-Rusch (1985) operationalized quality of life as the,

...manifest satisfaction of an individual with their life space, including their residence and its associated features, their friends, their community, and their opportunities (pg. 487).

Further, Powers and Goode (1986) and Goode (1987) generated a conceptual scheme that suggested that quality of life was "environmentally specific." That is, quality of life depended upon the part of a person's life under analysis, as well as the relationship that exists between persons in each of the environmental settings. These settings included the residential environment, the work or school setting, and the community setting. The interactive relationships between these macro structures were viewed as the key to understanding and measuring quality of life. Goode described this conceptual model as "client-centered" with his scheme focusing on specific settings and critical relationships in those settings.

Finally, Taylor and Bogdan (1990) regard quality of life as an "elusive concept" that is seldom used in studies focusing on persons who are non-disabled. Rather, it is employed only in situations where there is a perception that someone or some group is suffering. With respect to quality of life and those persons who are developmentally disabled, these authors see the concept as a double-edged sword. It can be viewed as a positive research interest by placing a focus on examining how much dignity and respect are provided these persons. In essence, the very act of measuring quality of life indicates and recognizes that in the past these person were denied such basic considerations. In
contrast, by attempting to measure the quality of life of the mentally disabled, researchers may be reinforcing the differences that exist between the so called "normal society" and those we label and dehumanize.

The Best Approach to Studying Quality of Life

So, with all of these ideas about quality of life, what is the best approach for examining the issues surrounding the concept? Most persons have a general idea of what it is to speak about or describe their quality of life experience. On the surface, the quality of life concept appears to be less elusive and more manageable when it comes to operationalizing and measuring the concept, but problems exist. Landesman (1986) appealed to the professional community, and in particular to the American Association on Mental Deficiency (AAMD) to develop an operational definition and to establish standardized guidelines for measuring it. In response to the challenge, Schalock (1990) developed quality of life principles which are offered below:

1. The study of QOL requires an in-depth knowledge of people and their perspectives;

2. The study of QOL for people labeled mentally retarded or disabled requires that the label be set aside;

3. The measurement of QOL should be tied to values and linked to measures of QOL for all the nation's citizenry;

4. The measurement of QOL requires multiple methodologies;

5. Family assessments that are driven by family choices and that are flexible, non-judgmental, and emphasize the development of family strengths must be developed; and
The application of QOL data is important in developing resources and supports for persons with disabilities and their families.

My study attempted to make use of these principles. For example, my years of experience allow me to engage in a level of comprehension and insight that meets the demands of understanding of the population in question. Also, I am keenly aware of the negative effects of labelling persons who are developmentally disabled. I am familiar with the "sub-culture" that exists within this population, including group-specific symbolism, the importance of the role expectations, and how the search for status, power, and prestige becomes a growing concern as more independence is gained. My background in human services also means that I have formed my own perspective on these issues. While I am aware of the problems of researcher bias, I believe that my first-hand experiences, including occasions to socialize and openly communicate with persons struggling with various developmental disabilities, affords me the opportunity and challenge to present a unique perspective.

Taylor and Bogdan (1990) presented what I believe is the most interesting perspective on quality of life with their methodological emphasis on individuality. One of their propositions is to suggest that while quality of life could be defined and studied in many ways, it is imperative to study it from the perspective of the individual. That is, it is critically important to understand and consider the subjective experiences and self-analyses that develop through qualitative interviewing strategies, i.e., life histories, open-ended interviews, and so forth. By following this methodology, these authors believe that
others will learn what quality of life means in more humanistic terms. While Taylor and Bogdan admit that trying to understand quality of life issues is difficult, they believe that evaluation data must originate from consumers themselves. They state,

....without an understanding of how people with mental retardation view and experience their lives, quality of life becomes at best a hollow concept and at worst a justification for treating them in ways that we ourselves would not like to be treated (pg. 39).

In particular, Taylor and Bogdan's individualistic approach offers several identifiable propositions which highlight and guide researchers in their quest to understand quality of life issues from the consumers perspective. These include:

1) QOL must be understood in terms of people's subjective experience;
2) QOL may be experienced differently by different people;
3) The study of QOL for individuals with developmental disabilities requires that the label be set aside;
4) Any inquiry into QOL issues concerning individuals with developmental disabilities requires looking at them from their perspective;
5) The study of QOL as a subjective experience may pose methodological challenges;
6) Study QOL requires an in-depth knowledge of people and their perspectives; and
7) Definitions and conceptions of QOL must respect people's subjective experiences.

I agree with Goode and Taylor and Bogdan in that any conceptualization of quality of life must be multi-dimensional and that a humanistic approach needs to be taken when developing an appropriate methodology. Most individuals with developmental disabilities
are aware of their lives at home, in the work place, and in the community where they live. In addition, it has been my experience that consumers are quite capable of expressing for themselves what they like or dislike about their lives in these three distinct dimensions. There are very few emotions that consumers have not had to deal with, including frustration and anger over various aspects of their lives. The research concerns pointed out by Goode and Taylor and Bogdan are of particular importance for both theoretical and methodological purposes.

For while some attempts have been made at establishing the quality of life as experienced by individuals with developmental disabilities, the literature offers only a few studies whose authors have tried to capture this from the consumer's perspective. Schalock (1990) discusses a few of these cases, including studies which focused on subjective well-being (Andrews and Withey, 1976), evaluation of life's critical incidents (Flanagan, 1978), satisfaction with home and friends (Heal et al. 1981), quality of life (Seltzer, 1981), and relative subjective well-being (Heal and Daniels, 1986).

In the past, researchers often relied upon the consumers' staff and significant others to describe and elaborate on topics related to their quality of life. However, as Landesman-Dwyer (1981) suggested some time ago, it is important to:

....assess the quality of life from the viewpoint of individual clients--their personal preferences, needs, and capabilities--rather than from our own perspective (pg. 231).

Therefore, in keeping with the numerous demands for a more individualistic approach to the study of Quality of Life, the methodology featured in this study will be aligned
with the contemporary movement by including persons with developmental disabilities as key respondents.
CHAPTER THREE
METHODOLOGY

Investigating the issues highlighted in the previous chapter required the employment of a wide variety of quantitative and qualitative research techniques. In essence, I opted to focus on the internal dynamics of one rather large residential service agency located in the midwest that offered residential services to individuals with developmental disabilities. While I did employ quantitative methods in this study by adopting a case-study approach, I was also able to triangulate information by collecting additional data through select qualitative strategies which permitted more in-depth analyses. Beyond offering me an organizational setting in which the normalization philosophy was employed, the agency provided me with access to all of its facilities, employees, and adult consumer populations. With respect to specific data collection techniques, I utilized content analysis of official documentation, self-administered surveys with employees, semi-structured interviews with staff and consumers, and, finally, spatial analysis of different residential settings. Details concerning methodological strategies, issues, and decisions are now presented.

A Few Words About the Target Agency

Certain financial concerns and time restrictions required that I make a few basic decisions about the research process. In particular, I resolved that I would collect data by incorporating efforts within a large, or extended, case-study format. In other words, I selected one agency from which to collect my data. The agency, one of the midwest’s
largest, most progressive residential agencies, employed 107 residential management-level and direct-care staff, and offered services to over 275 consumers, both children and adults. By focusing on a single agency, total access to documentation, facilities, staff, and consumers was granted more easily. The agency maintained diverse operations, providing residential services to children and adults whose disabilities range from severe and profound to mild forms of mental retardation. The residential facilities varied in construction and design and were dissimilar with respect to degree of restrictiveness. Facilities included traditional 11-bed group home environments, 5-bed waiver homes, apartment complexes, and scattered site apartments.

In addition to residential services, the agency offered a variety of supportive services such as counseling, guardianship programs, financial programs, physical disability support, and head-injury programs, to list just a few. For the purposes of my study, only the agency's residential service program was identified for use. The reason for this is simply that it offered the types of programming in which most indicators of normalization and quality of life issues will manifest themselves. For example, within the residential division of the agency was found the necessary data sources for my study, including official documentation, facilities, and the employees and consumers who shared a knowledge base of pertinent topics related to my study, e.g., leisure activities, residential conditions, social integration, abuse and control, and so forth. The agency represents itself as a strong advocate for the normalization philosophy and operates from a service modality that incorporates normalization's principles. Because of the sensitive nature of the topic, and because there is a need to protect the identities of all involved, it was
agreed in advance that the name of the agency and those of all respondents would not be disclosed.

The agency's staffing patterns are structured in a way that finds direct-care staff working with consumers at various residential settings around the community. These direct-care staff are divided into a three-status hierarchy. At the top of this direct-care staff hierarchy are the residence program managers (RPMs). These RPMs are responsible for most of the day-to-day operations, including residence administration and filing system, regulation adherence, and consumer programming implementation and monitoring. Below the RPMs are situated the residence program manager assistants (RPMA s) whose job it is to support the RPM. Often, the RPMA works when the RPM does not. RPMA s are trained to step in and perform in the absence of their RPM. Finally, at the bottom of the direct-care staff are the direct-care aides. These aides are responsible for doing whatever must be done at the time they work their shifts. Their tasks may include taking consumers out on shopping trips, working with various consumer programs, helping consumers with apartment clean-up, and other duties as assigned.

With respect to the residential department within the agency, all management-level employees are located at and work out of the agency's headquarters building. At the top of the residential staff hierarchy is located the executive director and the associate executive director. These persons are responsible for advocating for the agency, and seeing that the operation meets its mission statement goals, residential and otherwise. Under them is the director for residential operations. This person is responsible for all
operations which fall under the purview of the agency's residential program. Directly under this person are located several program directors who assist their director by monitoring and reporting on the day-to-day operations and administration of their respective residential programs. These programs include residential services and training for consumers who are head injured, mentally retarded adults, mentally retarded children, and those consumers who have been identified as both mentally retarded and mentally ill. Finally, located between the program directors and the direct-care RPMs are the program coordinators. Program coordinators are responsible for ensuring that direct-care staff are trained and performing their roles in an appropriate fashion. These employees are responsible for program development for consumers, training employees, and attending staffings as the member of the consumers' inter-disciplinary teams who is responsible for representing residential interests and concerns. They are, for all practical purposes, the agency's supervisors of all direct-care staff.

Questionnaire Respondents and Interview Informants

Prior to beginning this research project, a package was submitted to the Human Subjects Review Committee (HSRC) at Iowa State University which detailed the involvement of human subjects. The methodology and participation of all respondents was approved by the HSRC before work began on this project.

All of the 107 residential employees were given a letter of introduction which explained the purposes and intent of my study, along with providing each recipient with a copy of the self-administered questionnaire and a self-addressed, stamped return envelop. Of these 107 employees, 63 mailed back their questionnaire for a return rate of 59%.
Because 7 respondents failed to indicate their position within the agency, a complete breakdown of the respondents by job category was not possible. While the questionnaire contained only a few demographic questions, I am certain that one of the primary reasons behind the failure for some to respond to them was associated with the fear of self-disclosure. For the purposes of my study, these missing data were not viewed as detrimental. Of those who did respond to the demographic questions, 38 (67.8%) were direct-care staff, including 24 (42.8%) RPMs, 6 (10.8%) RPMAs, and 8 (14.3%) Aides. The remaining 18 (32.2%) employees were management-level, including 8 (14.3%) program coordinators, 5 (8.9%) counselors, and 5 (8.9%) program directors and directors.

All employees who took part in this study volunteered and were promised strict confidentiality. Because of the sensitive nature of the issues and the data sought, I made the decision to not associate any data with a specific position in my report and to refer to respondents as members of one of two groups - management-level employees or direct-care staff. If such assurances were not given, I seriously doubt if respondents would have taken part or discussed issues freely and honestly. I also made it clear that I would mix positions from time to time. For example, if a quote from an aide was used, I may have identified the person as a RPMA, or even a RPM. By following this method, I felt that it would be very difficult, if not impossible, for future readers to pin-point or place responsibility for any of the quotes on a particular person.

Opened-ended, semi-structured interviews were also used to collect data during different phases of my study. For examples, interview sessions were held with several
management- and direct-care-level employees, most often in order to help clarify information obtained by way of the employee questionnaire, e.g., internal and external obstacles, abuse and social control, employee relations and so forth. In addition, several RPMs provided insight when I observed different residences during the spatial analysis phase of my study. Finally, issues surrounding quality of life were examined by interviewing individual consumers in their places of residence. Deciding to interview individuals with developmental disabilities might be questioned by some. However, I felt that by doing so, I would be in a position to add to the literature on this methodological concern. Beyond the methodological interests, theoretical considerations already eluded to in the previous section, make using these persons critical to my study.

Using Individuals With Developmental Disabilities as Key Respondents

The viability of the process of normalizing individuals with developmental disabilities will be investigated through an examination of quality of life issues. In order to accomplish this, qualitative data was solicited directly from individual consumers vis-a-vis an open-ended, semi-structured interview schedule. Traditionally, methods that employed individuals with developmental disabilities have raised research questions concerning the validity of the data. That is, many researchers felt that persons classified as "mentally retarded" were incapable of offering valid research data. The primary reasons for this has been the belief that these individuals: a) lacked the ability to respond with credibility, b) were unable to comprehend abstract notions, and c) were insensitive to, if not totally detached from, much that surrounded them (e.g., see Beier et al. 1951; Atwell and Clabby, 1971; Sigelman et al. 1980).
No doubt, some differences must be taken into account, and certainly a few challenges are very real, but these things can be overcome by employing methods that are thoughtfully constructed. Some writers have highlighted the difficulties of involving individuals with developmental disabilities as informants in research. For example, Sigelman et al. (1980; 1981a; 1981b; 1982; 1983) discussed many of the pitfalls and frustrations of soliciting information from these persons. For example, such persons have shown a strong tendency to respond in ways they believed were expected of them. These authors demonstrated that all of their samples indicated a strong proclivity towards developing a systematic response bias.

In more recent work, Sigelman and Heal (1992) reported that this acquiescence bias tends to be exaggerated in respondents who reported having little education, came from a low socioeconomic status, and had low mental ability. In contrast, the authors found that those respondents who had been classified as higher functioning persons were less likely to follow a response tendency. Finally, these authors concluded that it is preferred if researchers employ an "either-or" format accompanied with supportive documentation, e.g., picture representations of choices. Similarly, and not too surprising, was the finding of Heal and Rubin (1993) who concluded that the wording of structured interview questions was critical to success in research that involved individuals with developmental disabilities.

While rare, research efforts have engaged individuals with developmental disabilities in quantitative research designs. For example, studies on assessing sexual knowledge (Hall and Morris, 1976; Edmonson et al. 1979), political issues and the retarded (Ryan,
1980), group home experiences (Heshusius, 1981), community residential adjustment
(Seltzer, 1981), behavior management (Foxx, 1982), general community integration (Heal
et al. 1988), life-enhancing activities for the elderly (Beisgen, 1989), parenting (Whitman
and Accardo, 1990), and assessment of life after deinstitutionalization (Lord and Pedlar,
1991) have all used individuals with developmental disabilities as primary respondents.
In keeping with the individualistic paradigm as exposed by Taylor and Bogdan (1990),
Schalock (1990), and Amado (1993), I opted to use individual consumers to examine
quality of life issues. In particular, I wanted to capture their home and work experiences
as described in their own words and from their own perspective, recalling that to do less
is to miss the true picture. Perceived or real, the quality of life as experienced by
consumers is the only one that should count under normalization.

The methodological concerns cited above, while real, were not of grave concern
during data collection. The reason for this is simply that planning allowed me to avoid
the pitfalls of utilizing lower functioning consumers as respondents. That is, with only a
couple of exceptions, my interviews took place with higher functioning consumers who
understood and grasped features of their life, and social reality in general, at higher
levels of abstraction. Whenever there was a question about comprehension, I followed up
with additional questioning in the area to ensure the validity of the data. As the data
presented in my report suggest, only rarely was such follow-up questioning deemed
obligatory.
Selection and Description of Consumers

Residential placement of consumers is carried out through a process of evaluation and observation. The agency recognizes three levels of ability in this regard including low, moderate, and high functioning. Quite often, an observer can find consumers grouped together by skill levels. For example, the lower functioning consumers are assigned to one of two group homes which have 24-hour staff supervision. Moderate functioning consumers can be found at traditional group home settings and 5-bed waiver homes. These residential settings also have 24-hour staff supervision, but there may be less structure in the homes. Finally, higher functioning consumers are usually assigned to apartment complex settings or, if and when judged ready, into their own apartments within the community. Ability in this sense should be understood in terms of skills and the ability to be trained. Thus, each consumer has the opportunity to grow and develop in as many areas as their abilities permit. It is also possible for consumers to advance through the system from very structured environments to less restrictive settings.

For the purpose of this investigation, only those consumers living on their own either in apartment complexes or in independent apartment settings were placed into a pool from which names were randomly selected for formal interviewing. The pool contained 74 potential respondents. These names were arranged randomly and then, using a table of random numbers, I selected the first participant and every third person from that point on until I had 24 names. This left me interviewing one-third of the higher functioning consumers within the agency. The rationality for following this selection method included the fact that: a) these "populations" were identifiable by the agency, b) most of
these person were their own legal guardians, c) most have arrived or were striving to achieve a high level of independence, and d) all participants were able to understand and respond to questions which use highly abstract notions.

As stated, I completed 24 formal one-on-one interviews which included discussions with nine males and 15 females. These respondents had an average age of 30.1 years. Twenty (83.3%) respondents reported that they were single, while two (8.3%) reported being divorced, one (4.2%) married, and one (4.2%) separated. Of the 24 interviewees, 19 (79%) reported having attended regular grade and high school. Of those who attended regular school classes, seven (36.8%) reported that they had not graduated while the other 12 (63.2%) did. One respondent reported being pulled out of school at the 2nd grade level. Others reported getting as far as 8th (1 respondent), 10th (2 respondents) and 11th grades (1 respondent). All five of the respondents who indicated that they had attended special education classes also reported that they had graduated.

With respect to income, this group of respondents were clearly confused, even embarrassed, by the fact that they were not sure what their annual incomes totaled. For example, one female responded that she made $840.00 a year, another male reported $600.00 a year, while another female gave a weekly income figure of $29.00. Frankly, it was apparent that none of the respondents knew their annual incomes. The fact they were unsure about annual income is not to say they were not capable of understanding, merely that it was clear that it did not appear as an important piece of information to know. None-the-less, the fact that they did not understand such facts was surprising given that most of these individuals were assigned to the least restrictive residential
program the agency offered, and, perhaps, reflects a lack of training and emphasis on staff's behalf.

Of the 24 respondents, 8 (33.3%) were unemployed at the time of the interview. The other 16 (66.6%) reported their regular job in the areas listed below:

- Fast Food Restaurant (salad bar, stocking and "prep" person) - 4 (25%)
- Restaurant Help (dishwasher) - 2 (13%)
- Janitorial Services - 4 (25%)
- Local Day Program (sorting pop cans to separating and sorting clothes) - 4 (25%)
- Worker in ice company (odd job man) - 1 (6%)
- Worker for local newspaper (insert work) - 1 (6%)

From this list of jobs, the consumer who held the job with the ice company was the only consumer with full-time employment and a full array of employee benefits. For the others, the work was part-time, ranging from a total of four hours a week, to approximately 18 hours per week. With few exceptions, these jobs were very much "type-casted," predictable employment patterns with low wages, no or limited benefits, and hot and dirty work conditions.

Living environments varied little, with 23 of the 24 respondents living in an apartment complex. It is important to separate these complexes into two types. Fifteen (65.2%) lived within an apartment complex that only housed individuals who were developmentally disabled, while 8 (34.8%) lived in apartments that were scattered throughout the city, independent from other consumers. The remaining respondent lived in a duplex. Most of the respondents who reported living in an apartment situation had roommates, or lived there with their children. Five (21%) of the 24 respondents were women who were living with their children.
Finally, at the end of each interview session, respondents were asked to rate what they believed was their general quality of life. For this purpose, I employed a simple scale which I drew during the course of the interview. The scale contained a single line, or continuum, and I explained that one end of the scale meant "just horrible" and the other meant "just great." To emphasize the extremes of the continuum, I drew a "happy" and "sad" face at each of the appropriate ends. This was the only "scale" I used during the course of my interview sessions with the consumers.

All of the 24 interviews took place in the consumers' residences and were carried out over a period of two months. All consumers selected volunteered to take part in my study. All interviews were taped and transcripts were made of each tape. Notes were also taken during the sessions. All consumers who took part in the study were promised confidentiality, and, in keeping with such a promise, any personal information that could be used to identify individual consumers was changed, including their names, and, in some cases, their sex. Additionally, whenever the data was deemed to be too specific, the information was either sanitized or omitted.

Analysis of Documentation

The first task for my research was to establish whether or not the agency had adopted the principles of normalization with respect to its delivery system. In order to arrive at a determination on this matter, content analysis of official documentation was employed. As part of the research strategy agreement worked out with the agency's leadership, I was given access to all agency documentation surrounding its mission statement and goals. I also examined a copy of the agency's Consumer Bill of Rights, a document that
covers the rights and privileges consumers are granted at the time they begin receiving services. While an important strategy, it was but only one of the means through which the agency's official position on normalization was established. For example, in addition to reviewing and analyzing the aforementioned documents, I reviewed the agency's long-range planning strategy which stressed options, choices, and participation for and by consumers. I also requested that respondents define normalization in their own terms and asked them to provide insight into how their attempts to normalize their consumers were blocked, in any fashion. Additionally, I used interviews with some employees to gain better insight into how successful or unsuccessful the agency had been at implementing the philosophy.

**Internal and External Obstacles to the Process of Normalization**

Obstacles to the process of normalization were viewed as anything that might act to impede the process of normalizing consumers. In order to begin my examination of internal obstacles, I focused my attention on four major areas: a) general staff attitudes toward their jobs and their consumers, b) topic-specific attitudes of general staff such as attitudes held by agency staff concerning the sexuality of their consumers, c) situations in which abuse or excessive social control were present, and d) spatial analysis of different types of residences. The specific methods used in this process are detailed below.

**General and Topic-Specific Attitudes**

Attitudes toward those labeled mentally retarded have always played a significant role in the quality of life experienced by consumers, e.g., the Eugenics Movement, widespread segregation, abuse and exploitation, and so forth. According to some researchers,
the misconceptions and attitudes held by both care-provider and the general public, while having changed, have not changed significantly, e.g., see Antonak, 1989; Bogdan and Taylor, 1989; Wolfensberger, 1992. Because attitudes play such a potentially important part in either increasing or decreasing the quality of life experienced by the developmentally disabled, a self-administered attitudinal questionnaire was distributed to all management-level and direct-care staff.

This instrument asked respondents to provide insight into the types of interaction, as well as insight into the openness and honesty with which staff approach their consumers. Beyond looking at interaction, the instrument also tapped different attitudes of the staff about the consumers. In addition to examining a series of general attitudes, it also asked staff to respond to a series of questions pertaining to attitudes about the sexuality of the consumers. Finally, the questionnaire asked staff to express their knowledge in the areas of abuse and excessive social control. This questionnaire, a copy of which has been attached as Appendix A, had the following sections:

1) Section One - asked respondents to provide their personal definition of normalization and requested that they provided what they considered obstacles to the process of normalizing their consumers.

2) Section Two - contained questions pertaining to how they viewed themselves as employees, their roles, and their work.

3) Section Three - contained general questions about staff attitudes toward several issues related to working with the consumers. The Community Residence Personnel Opinion Scale (CRPOS, Jacobson, and Mulick, 1990) was used.

4) Section Four - contained general questions about attitudes and opinions on a wide range of issues related to caring for consumers.
5) Section Five - employed Brantlinger's (1983) Sexuality and the Mentally Retarded Attitude Inventory (SMRAI) to measure employee attitudes toward individuals with developmental disabilities.

6) Section Six - requested staff to report on the amounts and types of abuse they were aware of and other questions related to abuse and excessive social control. In this section, staff were also asked to indicate in writing the different methods they were aware of in which staff excessively manipulated and controlled consumers.

7) Section Seven - requested brief demographic data.

The Community Residence Personnel Opinion Scale found under Section Three above is a multi-dimensional instrument. Specifically, it permits individual or group assignments (favorable or unfavorable) on 12 different areas of interest, including:

1. Negative Physical Care: attitudes toward providing care that involves such things as cleaning dirty or soiled linens, bathing ill consumers, and so forth.

2. Job Rejection: attitudes toward staff's agency and their particular job.

3. Push to Accelerate Development: attitudes toward ensuring that consumers are challenged with different environments.

4. Negative Ward Management: attitudes toward the amount and types of administrative chores staff must perform in their jobs on a daily basis.

5. Comradeship with Residents: attitudes toward developing a close relationship with consumers.

6. Job Insecurity: attitudes toward the agency and how they may be targeted for blame when things do not go right.

7. Institutional Identification: attitudes toward the public image of their agency and their role in supporting it.

8. Encourage Verbalization: attitudes toward encouraging consumers to vocalize their concerns, needs, and desires.
9. Irritability: attitudes toward the ease, frequency, and justification staff may hold when it comes to getting upset at consumers.

10. Equality: attitudes toward the power distribution between consumers and the staff who serve them.

11. Strictness: attitudes toward the position that consumers are often treated with too much tolerance.

12. Fostering Dependency: attitudes toward keeping consumers dependent upon staff rather than pushing them toward independence.

Attitudes Toward Consumer Sexuality

A separate section that focused on attitudes toward the sexuality of consumers was attached since the subject remains a hotly debated area, and one in which people’s attitudes can most decidedly impact upon the quality of life experienced by consumers. An assumption one might make about this topic is that those who work closely with consumers may form more liberal attitudes toward the topic, advocating for education and the privacy necessary for consumers to carry on a satisfying sex life. Traditionally, this has not been the case. For example, Heshusius (1982) reported that staff attitudes against sexual experimentation and intimate behavior amongst their clients led to staff behaviors which precluded situations from arising. If they did occur, the residents were often reprimanded or publicly criticized. Similarly, Coleman and Murphy (1980), discovered that residential staff often discouraged, and even prohibited in some cases, residents' sexual behavior that went beyond the act of masturbation.

Brantlinger (1983) found that residential facilities seldom have formal, written guidelines for staff to refer to when it comes to sexual matters involving their residents. In lieu of formal guidelines, staff were often left to handle sexual situations as they
deemed appropriate, often with horrible consequences for consumers. In addition, Brantlinger (1985; 1988) established that there was a growing need for sexual education among the mildly mentally retarded, and that, when provided, most information was limited in scope and often distorted. Lastly, negative attitudes have led to serious consequences for the developmentally disabled, including the Eugenics Movement earlier this century. While many people might consider involuntary sterilization a thing of the past, studies in the 1970s, revisited the issue of voluntary sterilization as a preferred method of birth control.

Whitcraft and Jones (1974) reported that 85.8 percent of the 652 parents and professionals who responded to their questionnaire "favored" and "strongly favored" voluntary sterilization for persons with mental disabilities. Such a drastic method of birth control must certainly reflect underlying attitudes about persons who are developmentally disabled becoming parents. Likewise, Vitello (1978) offered a review of the then current literature for and against involuntary sterilization. Persons whose attitudes support involuntary sterilization argued that such action would act to serve the best interests of the state by reducing the number of mentally retarded persons in America, and, thus, increase the quality of life the normal population experiences.

The Sexuality and Mentally Retarded Attitude Inventory was modified in order to be made more applicable to residential settings. Brantlinger's original scale contained 45 items which she later reduced to 40. The modified version I employed contained 25 items. As with Brantlinger's versions, I used a Likert-style scale with each item weighted from one to four. The liberal and conservative direction weighing depended
upon the specific question. Depending upon respondents scoring, each was assigned to either a liberal or conservative group. After the necessary recoding for response direction, a perfect "liberal" score was 25 and a perfect "conservative" score was 100. The SMRAI was made part of the larger self-administered questionnaire, and, as such, appears in Section 5 of Appendix A.

**Spatial Analysis**

According to Johnston (1973) and Wolfensberger (1975; 1977), traditional concerns over institutional environments take three things into account: 1) role expectancies, 2) the impression or meaning conveyed by the facility, and 3) convenience. With respect to role expectancies, institutional design can either add to or detract from the amount of physical freedom and privacy experienced by consumers. This is of concern when taking into account the design of traditional group homes in which up to eleven consumers and one 24-hour staff person live. Consumer role performance is not only influenced by the interaction between themselves and their direct-care staff, but by the physical constraints imposed by a given facility's design. This may be especially true when it comes to separating public and private areas within a communal living arrangement such as the ones found in both group and waiver home environments.

Wolfensberger also believes that with respect to image, facilities can, and often do often project different impressions. Some buildings may be constructed and designed as a monument, others may reflect an effort at public relations, and some may be built with service in mind. In addition, convenience is also a factor that plays a role in a building's construction. Differences in housing size, quality, and types impact upon the care of
consumers and has been examined by many in the field (e.g., Bjannes and Butler, 1974; Balla, 1976; Baroff, 1980; Landesman, 1987; Felce, 1987). Generally, research has repeatedly demonstrated that smaller residential environments are associated with increased opportunities for community integration and socialization, more one-on-one interaction with staff and more privacy.

In order to examine whether or not residential environments either add or detract from the normalization process and the quality of life experience, a basic form of spatial analyses was performed on different types of residential settings the agency offers consumers. To assist me in this endeavor, I used a modified version of the Characteristics of Physical Environment or CPE (Jacobson and Ackerman, 1990). Specific issues in this instrument included: a) characteristics of residence, b) normalization of physical environment, c) community and neighborhood, d) neighborhood characteristics, e) residence fit, and f) house rules. Of particular interest was the normalization of physical environment. This scale consisted of eleven items including:

1. Inside homelike appearance
2. Cheerful, warm interior
3. Individually decorated bedrooms
4. Homelike appliances and fixtures
5. Comfortable, non-standardized furnishings
6. Age-appropriate environment
7. Normal risk-taking fixtures
8. Outside lawn appearance
9. Private storage for personal items
10. Flexibility of interior design
11. Design conducive to privacy

In my modified version of the CPE, each of the above items were rated on a "yes" or "no" basis. While Wolfensberger and Thomas' Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING; Wolfensberger and Thomas, 1983) provides methods for evaluating the physical environments found in residential settings, I felt that a simple dichotomous rating system was preferred for my purpose. I arrived at individual residential ratings on these items after completing observations of each of the residential neighborhoods, as well as the residence's exterior layout and interior spaces. While certainly subjective in nature, each of the above listed eleven items is clear with respect to what constitutes a "yes" or "no" response, e.g., either the interior design of the setting could be changed or it could not, consumers could decorate their bedrooms as they wished, or there were restrictions, and so forth.

For example, group homes did not present a homelike appearance inside. They were large buildings with staff apartment areas, large living and dinning areas, separate dormitory wings, large, semi-private bathrooms, and one large recreation room. In contrast, waiver homes and the apartment settings offered consumers very normalized, homelike appearances inside and out. In addition, nothing about these settings would suggest that the structure was used for anything special or indicate who occupied the dwelling. So while some might claim that these spatial analyses were some how "tainted with subjectiveness," I would only offer that they reflect an accurate picture and
accounting according to the goals of normalization. During these residential examinations, various housing staff were asked to take part in unstructured interviews. These interviews pertained to house rules and the staff's general impressions of the operation of the agency and their residence. A copy of this CPE instrument is attached to this report as Appendix B.

**Quality of Life Experiences**

Quality of life issues were examined by interviewing a randomly selected group of consumers. Beyond the theoretical importance of this portion of my study, the segment also holds methodological significance. Most studies which have examined quality of life issues gather data from direct-care staff and other significant others. While some feel that this strategy is methodologically sound, I felt that it would be more meaningful to ask consumers themselves for evaluations. As pointed out in the introduction, Landesman-Dwyer (1981) suggested that researchers used residents as key informants when examining quality of life issues. I hoped that by following these authors' lead, my study would offer new insight on methodological issues that are considered somewhat unique in the literature.

By collecting data directly from consumers it allowed me to establish the degree to which normalizing behaviors were engaged in at all three levels: the individual, the organizational, and the societal. The qualitative guide employed included questions that represent the multi-dimensionality of quality of life, especially the areas of home life, work environment, and social and community integration. As earlier stated, one of the major purposes of this study was to examine the outcome of normalization at the direct-
care level, i.e., what is reality like from the consumers' perspective. Staff members always seem to have an opinion about how good or bad life really is for their consumers. But do they possess and articulate an accurate picture? Hearing responses to questions that tap into quality of life issues will help answer whether or not they do. A copy of this unstructured interview schedule is attached as Appendix C. All interview data collected for this study were analyzed by examining transcriptions for patterns of similarity and differences. Where such patterns were found, selected examples were used to illustrate such events.

Participant Observation

I believe that a word about my own work experience is required. Since October of 1986, I have worked within the human service field with adults who have been classified as developmentally disabled. Thus, attempting to approach this study from a purely objective perspective would be impossible. However, personal background provided a plethora of insider facts and figures, information and stories, and a certain degree of credibility when it came to interviewing respondents. Thus, I could question responses and probe when I felt the entire truth was lurking somewhere just below the surface. The knowledge, much of it coming from societal-level experiences, that I have will assist me greatly in analyzing the data and allowing me to offer detailed examples of situations which otherwise might not be included, e.g., formulating findings for all three levels of the concept of normalization, and so forth. In addition, I was able to discuss topics with consumers in relaxed confidence, whereas others might have found these situations uncomfortable, alien, or even hostile.
This study had three primary research objectives with respect to normalization. The first was to establish whether or not the target service agency employed the basic tenets of normalization as its primary service philosophy. The second was to determine the degree to which normalization had been implemented. Finally, I felt it was important to discover whether or not internal or external obstacles existed which might act to hinder the implementation of the normalization process. The first two concerns are examined in this chapter, while the third objective is considered in Chapter Five. Toward these ends, several types of data collection methods, both quantitative and qualitative, were used as a way of increasing the number of conceptual indicators for examining these important issues. Initially, content analysis of the agency's official documentation including its official mission statement, a Residents' Bill of Rights, a Policy Manual, Long-Range Mission Plan Statement, and other agency documentation was used. These data provided insight into the agency's official position with respect to normalization. These data were combined with interview data collection efforts with different residential employees at all levels.

Normalization: Its Presence and Priority

After analyzing the content of the official agency documentation, I arrived at the finding that normalization is the primary service philosophy that drives the official residential service goals set forward by the agency. Several passages extracted from the
agency's policy manual acknowledge the philosophical underpinnings on which normalization is based. For example,

The agency's policy has been to meet the special needs of those persons having disabilities....allowing the person as much involvement in decision-making as possible, and directing efforts toward the least-restrictive alternatives for the client (Policy Manual, pg. 1).

Evidence of this is demonstrated by the agency's impressive range of service offerings, including referrals, intakes, individual and group counseling, family support services, health services, food programs, parenting skill training programs, transportation, as well as a wide range of residential service options ranging from traditional group home environments to an significant independent living apartment program. Care in evaluating for placement within the residential program was also evident and in keeping with the idea of normalizing individuals with developmental disabilities. For example, the official, overall purpose for residential services is,

...to assist the person, family, or group member to achieve greater self-sufficiency, understanding of the community, and gain self-confidence (Policy Manual, pg. 15).

In addition, the spirit of normalization is contained in passages which draw attention to the effort and general aim of the agency's residential services. They conclude that,

Individuals are screened and placed at an appropriate level and are then trained to develop as many independent living skills as possible. As a person's needs change, transfers are made throughout the system as well as referrals to other appropriate programs. An atmosphere of positive reinforcement emphasizes strengths and abilities in dealing realistically with the areas of need (Policy Manual, pg. 15).
Also,

The group of services offered are designed to help persons who have a disability to succeed in community living and to promote their participation as community residents. Individuals are helped to become as independent as possible in the areas of self-care, grooming, room maintenance, laundry, community mobility, meal planning and preparation, socialization skills, money management, and community activities (Policy Manual, pg. 17).

In addition to the agency's official policy manual statements, there existed an agency document entitled, "Residents' Bill of Rights." This single-page document contained a comprehensive list of legal, human, and personal rights, as well as outlining residents' responsibilities required for their maintenance. According to management-level staff, early on in the consumer intake process the document is explained in full. For example, each individual right is explained in full and consumer questions concerning them are answered. Once the form has been discussed, new consumers are required to sign a copy of the document, indicating that they received the briefing, were allowed to ask questions, and understood the document's content. An official position statement concerning these rights is included within the document:

.....each resident has the right to considerate and respectful care and to be treated with honesty and dignity. It is recognized that every resident is an individual who has feelings, preferences, personal needs, and requirements (Resident's Bill of Rights, 1993).

Taking into account only a few of these rights clearly differentiated the services offered by the agency and the nature of the services found at many of the larger, state-sponsored institutional settings. These items included such rights as: a) the right to manage one's own finances, b) the right to privacy in treatment and care and during
personal visitations, c) the right to respect and confidentiality in treatment and care, d) the right to communicate and meet with persons of their own choosing in public and in private, and e) the right to be free of mechanical, chemical, and mental restraints or abuse, just to list a few.

Passages such as the ones cited above, and the steps taken during a new resident's intake process show the type of care and concern the principles of normalization would call for and appear to be in keeping with the agency's mission statement. However, while the list of rights granted to consumers was comprehensive, specific wording found in the Bill of Rights often was vague and contradictory. As I examined certain passages further, I began to wonder how these many rights were translated and merged into the agency's delivery system at the direct-care level. This observation stems from passages such as the one that discussed the right to associate with whomever the consumer desired. The passage that discussed the right went on to stipulate that the right would be granted to the consumer,

....unless to do so would infringe upon the rights of other residents, of if so indicated and documented by a Qualified Mental Retardation Professional, IDT (inter-disciplinary team), or physician in the resident's records (Resident's Bill of Rights, 1993).

In addition, it appeared that residents may, in some cases, unwittingly sign away their rights. For example, when it came to the rights covering finances, programming, and personal clothing usage, residents were given rights unless to do so had been blocked by an approved Individual Program Plan (IPP) of treatment, or some other form of agreement between the agency and the resident. In addition, terminology such as
"reasonable access to a place to receive confidential telephone calls," appeared ambiguous and certainly leaves a lot to the discretion and interpretation of the direct-care staff. After all, what constitutes reasonable access for one person may not for another. Further, several rights, including knowing about medical conditions, privacy of treatment, receiving visitors, and social activities could be restricted if a Qualified Mental Retardation Professional (QMRP), members of the resident's IDT, or a physician deemed it inadvisable for the individual. Lastly, when it comes to having protection against unnecessary restraining, the Bill of Rights states that such protection will be offered unless there comes a time when a consumer may need assistance in gaining control at which time staff can implement "client management" training techniques. Once again, rights were granted, but they remained something that could be restricted or even suspended at the discretion of various interested parties, both agency and non-agency alike.

Transforming Official Policy Into Direct-care Programming Reality

Having the tenets of normalization appear in print, even as much as the agency appears to have done, is only one step in the process. Ensuring that agency staff at all levels understand and incorporate the attitudes and efforts necessary for transforming them into agency direct-care programming is another. Thus, another issue is whether or not the staff really understood what was meant by normalization, and if they held similar definitions. If employees are expected to adhere to and incorporate the tenets of normalization, they need to have a firm grasp of the concept, what it means and how it is to be applied in their role as service providers. Directors need to instill the proper
conceptualization in their supervisors. In turn, supervisors need to educate and help ensure that such interpretations manifest themselves in the training and services managed by the direct-care staff.

One of the first goals of the self-administered survey given to residential employees was to discover what normalization meant to the employees. It did so by offering each respondent the opportunity to provide a written definition of the concept. In addition, each respondent was asked to list what they considered obstacles to the process of normalization. Fifty-two (82.5%) of the 63 respondents provided definitions of normalization. The results of this inquiry are displayed in Table 1. The spirit of normalization appears to be understood by most of the agency's residential staff employees. Other, more individually defined elements were also offered by many of the respondents, including items such as: a) holding consumers accountable for their actions, b) making consumers feel comfortable in offering their opinions on subjects, c) treating consumers with respect and dignity, d) helping consumers to integrate into their wider community; and e) helping others to learn not to define consumers by their disabilities.

Having established that staff at all levels were familiar with normalization and how it was and applied in their particular work levels, I wanted to examine more closely the agency's official position on its service ideology. Toward exploring this concern, I interviewed one of the higher-ranking management-level employees. This employee began by outlining the agency's ideology. When asked about the idea of normalizing and the potential difficulties involved, the employee immediately drew attention to the complexities found in the normalization process:
Table 1. Most Common Elements of Normalization as Defined by Agency Staff

Question Asked: What does normalization of individuals with developmental disabilities mean to you?

* Most Common Response Elements:

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Element</th>
</tr>
</thead>
<tbody>
<tr>
<td>58%</td>
<td>1. Offering consumers least restrictive environments, giving them rights and giving them the same opportunities as those offered the non-disabled population.</td>
</tr>
<tr>
<td>29%</td>
<td>2. Presenting consumers with opportunities that will allow them to go as far as their capabilities will carry them.</td>
</tr>
<tr>
<td>19%</td>
<td>3. Providing consumers with opportunities and challenges from which to experience and learn about life.</td>
</tr>
<tr>
<td>19%</td>
<td>4. Offering consumers real-life experiences and settings.</td>
</tr>
<tr>
<td>10%</td>
<td>5. Assisting them to develop skills that will allow them to function as normal in their community.</td>
</tr>
<tr>
<td>10%</td>
<td>6. Presenting consumers with social activities which are not just for disabled persons.</td>
</tr>
<tr>
<td>8%</td>
<td>7. Deinstitutionalizing individuals with developmental disabilities.</td>
</tr>
<tr>
<td>8%</td>
<td>8. Making consumers part of their own decision-making process.</td>
</tr>
</tbody>
</table>

N=52

* Respondents often presented more than one of the above responses.
You've [referring to this investigator] been around and know that these issues [issues surrounding normalization] are not of the black and white variety. Offering services to individuals with disabilities is never a simple chore, especially when you have so many agencies and other interested parties involved in the process. However, we do stress cliental rights and demand that all our people [resident consumers] are treated with respect and dignity (Respondent M-7, 1993).

And when addressing questions about the agency's Bill of Rights:

Let's not kid ourselves. Granting rights to the disabled is extremely difficult given the kinds of disabilities encountered by our organization, but we do our best to provide a living environment that presents them with the least restrictive environment possible. We have a list of rights that we guarantee clients, and they have the right to officially raise any concern they have, even to our executive director if they should so desire (Respondent M-7, 1993).

For their own safety, and for our own legal responsibilities, there are times when rights might be temporarily suspended because clients' emotional and physical states change over time. But we never engaged in wholesale neglect when it comes to rights. Anyway, when we have a question about infringing on rights, we place the need in the form of a program plan and the clients receive an explanation and have to sign the plan, acknowledging that they accept the plan. At that point, the clients take us officially off the hook (Respondent M-7, 1993).

These interview data certainly indicate that while the employee acknowledged that normalization is the agency's service goal, they also demonstrate the many complexities present in the process. Having worked in direct-care positions for many years, I recognize what these complexities are, as well as the frustrations surrounding their utilization. For example, the employee draws attention to the fact that rights are "conditional" due to the external pressures placed upon the agency from a wide array of sources. These can include over-protective parents and other legal guardians who do not share the agency's more liberated position on granting rights. In addition, even parents who are not the legal guardians of their son or daughter can bring pressure to bear on the
agency. This is especially true in situations when the agency believes that it is in their best interests to maintain a good working relationship with the parents. Unfortunately, such appeasement may be at the cost of the consumer's rights. Obviously, legal guardians have profound, direct power to maintain their desires and control over the consumers in question.

The other concerns stemming from conversations with staff members have to do with the agency's ability to manipulate situations through the creation of Individual Program Plans (IPPs) that, in effect, permits consumers to cancel their own rights by signing on to them. In such cases, not only are consumers made responsible for the removal of their rights, but the agency is, as the employee put it, legally "off the hook." While this strategy might be tried, it would be difficult since most, if not all, consumer programming must be tabled for approval before the inter-disciplinary team. This fact makes it unlikely that agency employees would get away with the wholesale restriction of consumers' rights via modification of IPPs. However, since direct-care staff are responsible for the daily charting and reporting on consumers, it is certainly within reason to believe that charting and reporting can be skewed in a manner that presents an image of a consumer who is in need of some form of behavior modification programming.

Perhaps of greater importance is what direct-care staff feel about the rights granted to their consumers. After all, these employees are the ones who have daily contact with the consumers. Thus, often it is up to these staff to work through any difficulties when and if they arise. Because of their position in relationship to the consumers they serve, these
employees can possess and utilize powerful influences over the consumers they serve. Additionally, through their attitudes and actions they can either promote or stifle the process of normalization. With respect to rights as an indicator of normalization, one residents program manager stated:

The entire issue is complicated and there are no easy answers. I think that my clients should have rights, but there are many times I have to direct them in their activities. Some people would think I am really controlling them. However, I do believe that all clients should be treated with respect and dignity and if that means giving them rights, then that is what must be done (Respondent S-57, 1993).

When another RPM was asked whether or not he or she manipulated or acted in a coercive manner toward his or her consumers, the RPM responded with an account of a situation having to do with a dating couple. The problem was that this couple lived in the same residence:

When I worked at a different house I was told by my supervisor that I had two months to break up a relationship that had begun between two of my clients. I was told that if I was not successful that one of the clients would have to be relocated. The company hates having to do that because of the expense and they end up having to explain things to parents and it gets kind of messy. It took me most of the summer, but I did manage to pull it off (Respondent S-1, 1993).

When asked about the role this RPM had to play in the entire affair, the RPM stated:

I really felt bad about my role in that thing. What I hated most was knowing that I was personally responsible for many of the tears and real emotional anxieties that my residents were coming to me with, not knowing that I was the cause of their trouble. It was kind of sad (Respondent S-1, 1993).

A management-level employee was asked about how such a situation as the one just described could come about. It became apparent that there was some type of unspoken or informal rule or guideline that specifically denied consumers who lived within the same
residential setting the right to date one another, no matter if they formed an emotional bond or not. When asked, the employee explained:

We attempt to ensure our residents understand their emotional and physical development and the changes they experience at different times in their lives. Sex is a tough issue since most of our residents live as groups, often sharing bedroom arrangements. We do not discourage sexual relationships, but neither do we encourage them. We have a standing rule that applies to group living situations and that is that residents who live in the same residence cannot date each other. This helps eliminate many of the jealousies and emotional highs and lows that accompany these unions. Each client has this explained to him or her upon entering our residential program (Respondent M-7, 1993).

Under the tenets of normalization, it would seem obvious that least-restrictive environments need to be free from excessive consumer manipulation. Having gathered data that suggested consumer manipulation takes place, RPMs and Residents Program Manager Aides (RPMAs) were asked about manipulation of their consumers. One RPM gave the impression that social control was a fact of life for consumers, and that accepting and going along with such social forces was part of a consumer's role expectation. The RPM stated,

I'm afraid that social control will always be a factor for the disabled to deal with. Society is not ready for people like the disabled to be given full rights. I mean my company finds it difficult to work with neighbors in an area where they want to open up new homes for our people. I mean, if people don't want retarded people living next door to them in a regular home, do you think they would agree to have them walking around with equal rights and no one looking over their shoulders? Social control happens most of the time in the company (Respondent S-5, 1993).

I talk with other counselors and supervisors and I know that it is widespread, but we are told not to think about it like that and we aren't to talk about it in public. A lot of what happens takes place behind closed doors. I mean decisions on how to handle certain people and what actions
to take have both a formal and informal side to them. There are certain things we don't talk about (Respondent S-5, 1993).

When asked for an example of the specific types of manipulation or social control the RPM was really referring to, the RPM offered a general example that concerned abuse:

Things like sexual abuse, physical and emotional abuse. I've turned in people for things. I am suppose to, but it often gets covered up and you never hear about it. After a while you learn that they [the agency] really don't want to hear some things that you want to tell them. It means they have to react and they don't like to have to react to things. This agency has a reputation among staff for "killing the messenger" when it comes to delivering bad news (Respondent S-5, 1993).

These disclosures point to the fact that there appear to be significant differences between the agency's official statement about accepting and implementing the tenets of normalization. Follow through by employees, as well as the structural difficulties encountered in trying to implement them, emerge as serious threats to the entire process. These comments also indicate that there may be what some refer to as a "formal" and "informal" side to the agency. If true, one of the more alarming points of interest is that employees may wish to follow through and protect their consumers from excessive manipulation and social control, but on the other hand, may interpret the agency's "informal" policy as one related to "we don't want to really know so don't bring things up that might make us react."

Having worked for years in the field, it is true that once a situation of alleged abuse is reported to the Department of Human Services, an investigation must proceed. In some cases, this process may involve public disclosure and even the temporary laying off of those employees reportedly involved in the case. It is easy to understand why an
agency might wish to proceed with caution given the realities of reporting and carrying such cases forward to their appropriate end. However, when an agency makes its employees feel like they cannot, or better not, report situations in which consumers are treated in questionable fashions, something is wrong.

One management-level person informed me that at least one high-ranking agency official had been responsible for the fact that one consumer had suffered from repeated sexual abuse perpetrated by the consumer's employer. This employer was a highly "respectable" person in the community, held an important position within county government, and was a successful business person. This employee stated:

I believe that [name of employee] is responsible for the sexual abuse that [name of consumer] experienced. The abuse was reported by [name of consumer] and [the name of the employer] was called in to the agency. [Name of employer] is an important county official who happens to own [name of business where consumer is employed and where abuse reportedly took place] (Respondent M-8, 1993).

Instead of taking care of the situation, [name of agency employee] asked this jerk to promise to not sexually abuse her again. God! The guy was getting blow jobs from this consumer and [name of agency employee] didn't take further action! So the guy was let go and the consumer was sent back into the same place where the abuse had taken place. I still can't believe it (Respondent M-8, 1993).

Well, guess what? It happened again, but this time the consumer's parents are taking the guy to court. How could [name of agency employee] let it happen? She may be in trouble anyway because I think the family is aware that [name of agency employee] failed to take appropriate action. Besides, [name of agency employee] will probably be called as a witness. Anyway you cut it, the agency is going to look very foolish. [name of agency employee] deserves to get her ass burned big time for this. She deserves it (Respondent M-8, 1993)!
Another management-level employee told me of a similar situation involving the same high-ranking agency official. In this case, the official was made aware that a direct-care staff had sexual intercourse with a female consumer. Rather than bringing state officials in to charge the perpetrator with the crime, the agency official quietly fired the staff member. Not long afterwards, this same abuser was hired by another human service agency. If these accounts are true, they smack of serious criminality and neglect and it certainly would make the agency and its leadership appear very foolish. Of all those who are charged with mandatory abuse reporting responsibilities, those working in residential services are some of the most important players. If consumers and their families cannot count on the agency and its employees to fulfill its reporting responsibilities, then on whom can they really count? If true, it also calls into question the commitment the agency really has to the normalization process. Another account by a RPM further highlights the dilemma faced by direct-care staff when it comes to reporting:

I know that one of my fellow employees is abusing consumers. They tell me what she does to them. But the last time I tried turning her in for the same thing and not doing her job good, I got shit on by [name of supervisor] and [name of program director]. I was made to look like the bad guy. These guys questioned my reason for bringing such things up to them. I mean, they thought I was trying to get the person in trouble and I ended up looking bad. I was just trying to do my job but not again. I learned my lesson with this agency (Respondent S-57, 1993).

A few RPMAs offered their opinions with respect to other situations in which excessive social control was used. These are the direct-care staff who often have the most contact with consumers. When asked about social control, one aide said,
I think its different for all of them. Its like eating. Some people can't even do up a menu and shopping list so I just go for them. If they got rights, I don't see them. People talk to them like they were babies or something. Supervisors talk to them like babies, even. You need to tell these guys like it is. I got a client who I would like to knock her head off. Her mouth in public is bad (Respondent S-2, 1993).

I don't know what to teach them because I don't have much education, but I don't think normalization works. We got this client who calls up people and talks to them in bad ways. The police found out about it and it was covered up. That ain't no way to get them to act up normally (Respondent S-2, 1993).

You talk about rights, and I think they got too many choices now if you ask me. They shouldn't have so many choices, even like having a beard because if they can't clean it, then they don't get it. If somebody has to take care of them, like cleaning their beard, then they shouldn't get the right to wear one. I know one woman I work with don't let them watch certain movies when she works. You know, those "R" rated ones, but I wouldn't want some of the guys I work with watching them either (Respondent S-2, 1993).

Although this information comes from only one direct-care aide, it offers a glimpse as to just how far removed the reality "at the top" is from the reality "at the bottom."

What appears certain is that if staff attitudes like those reflected in the above cited interview passages are wide-spread, then chances for normalizing consumers may be greatly reduced, and, more importantly, there would appear to be significant differences existing between the image the agency might prefer to project to the wider public and what really happens below the surface image.

For example, if a consumer is suppose to learn how to groom his beard with the help of a direct-care employee, but the direct-care employee does not want the consumer to sport a beard until he learns the necessary grooming techniques, then it is clear that the consumer will not be allowed to grow a beard. Or if he elects to do so, the quality of
training that needs to go along with his request may not be adequate. Whether or not similar attitudes may held by employees throughout the agency is left for the analysis of attitudinal data which comes at a latter point in this report.

Finally, the language contained in the agency's Long-Range Mission Statement and the messages delivered by the agency's executive director during a recent all-agency meeting both supported the idea of normalization and empowerment of consumers. According to the director, the agency exists primarily to support consumers, their families and children. For example, according to the director, consumers were to be empowered with the ability to determine both their residential setting and the direct-care staff who offer them support and training. In reality, neither has this been the case, nor do I feel is it every likely to come to pass. For example, just recently the agency had the opportunity to ask several consumers for input about their residential situations with regard to their preferences for the staff who serve them. However, instead of soliciting this type of information from consumers, a small group of management-level employees decided which staff members were going to work with which consumers. Thus, rather than following the new official agency commitments to their consumers by offering them the chance to make real choices, the agency opted to once again act on their behalf and just hand down these decisions to consumers.

**Normalization of Consumers: A Matter of Personal Perspectives**

As just stated, the data illustrate that competing social realities may exist within the agency, and that these competing visions can be separated along employee lines. For example, the reality often expressed by the agency's leaders and some in management
positions is very optimistic with respect to normalization. They see normalization as an achievable goal which is very beneficial for the consumers. The agency continuously emphasizes the fact that they "put consumers first," and that consumer needs act as the force which guides the agency. Some in management and many in direct-care work feel quite differently. For them, it is clear that the agency does offer its consumers a better life than they would have if locked away somewhere in a large, impersonal institution. However, they disagree with the agency's leaders when it comes to the degree to which the agency really does what it claims. This competing perspective suggests that there is very little "normal" about the way the agency goes about normalizing its consumers, and that much of what the agency allows to take place works to hold consumers back. I will now turn toward an examination of these competing realities.

**Reality at the Top Versus Reality at the Bottom**

One reason for why organizations come into existence is for them to serve social needs and to spur on social change (Hall, 1987). Initially, human service organizations were used to warehouse individuals with developmental disabilities. Since the 1960s, and with the advent of normalization, human service organizations that offered residential services sprang up all over the United States. These agencies offered smaller, more normalized residential environments in which to live. They offered personalized service options to consumers who, for the first time, were treated with respect, dignity, and trained in social and living skills while preparing for a more independent lifestyle. In order to receive funding from a variety of sources, these organizations were required to demonstrate that they were following these new philosophical guidelines. Thus, directors
of these agencies had to construct, sustain, and represent a very particular image to the outside world.

In the present case, this image is one of the agency meeting and fulfilling the needs of the consumers whom they serve by assisting them in becoming as individually independent as possible. According to official agency documents this is, in fact, the primary goal captured in the agency's mission statement and its long-range planning program. It stipulates that the target agency's purpose is:

To foster the active community participation of people with disabilities and expand child care options to families. The agency affirms that all people:

a. have inherent value, giftedness, and capacity to grow;

b. should have access to an array of services and supports in the community of their choice;

c. should be empowered to make their own choices about where to live, work, and spend their leisure time; and

d. should be provided opportunities for a typical home, meaningful employment, and participation in community life (Agency Long-Range Mission Statement, pg. 1).

In an effort to promote these service ideals, the executive director of the agency recently held a meeting which I attended. To assist members of the audience in understanding the agency's purpose and how it views those persons it serves, the director distributed a handout that clearly indicated that the needs of each consumer and his or her family were to be prioritized. In addition, the director produced an organizational chart that had "People With Disabilities Families And Children" within the box in the upper-
most position on the schematic; the position normally reserved for the chief economic officer. The director elaborated on the chart, exclaiming:

The manner in which we serve our consumers is both evolutionary and revolutionary. We must be reactive. We must control both circumstances and conditions. What were the values in America thirty years ago? People were calling our consumers idiots, imbeciles, morons, and other dehumanizing names. We've helped to change all of that. As an institution of care, we have gone from taking care of these people to supporting them and giving them control over their lives. We give them the power to decide where they want to live, where they want to work, and with whom they want to live and from whom they receive services (Respondent M-2, 1993).

Staff members who listened intently to his words were moved to agreement as the gathering recognized their unity of purpose. There is no doubt that the agency assists individuals with developmental disabilities in many areas of their life. One very real example of this involves how the agency assisted one consumer in his efforts to purchase his own home. This was accomplished over a period of many months, but it was an effort that was seen through to its completion. The consumer will be moving into his home within a couple of weeks. And there are many other individual success stories, even if they are smaller by comparison. Recently, one of the local newspapers featured an article that centered attention on how one of the agency's consumers had arrived at retirement.

The article discussed how this consumer had developed into a very independent person after having spent much of his youth in one of the larger, state-sponsored institutions. The article stated,

Robert got his start in the system at [name of state-sponsored institution]. The kindest thing that could be said about the place was it was a human warehouse and worse. The people living there were not treated as people.
He was just one of many who went there because that's where you put people who weren't quite the same and the family couldn't care for them (Newspaper, pg. C1 and C5, November 25, 1993 edition).

Part of the impression the agency's leadership strives to incorporate in its public image is one of consumer inclusiveness. In attempting to retain this image, the agency's management-level leadership core, defined as members of the board of directors, the executive director, associate directors, program directors, and program coordinators, believe that by providing consumers with education and necessary information that they will become self-empowered. This empowerment will allow consumers the opportunity to become more involved as self-advocates in important decision-making processes. The agency has highlighted goals which should help it accomplish these things:

a. to include consumers on all agency boards and committees;
b. to educate employees about agency philosophy and goals;
c. to develop a human rights committee to review consumer rights and choices;
d. to develop a sexuality rights policy to be adopted by the board of directors;
e. to expand opportunities for community integration through increased utilization of volunteers; and
f. to foster consumer and family awareness of services and support systems available through the agency (Agency Long-Range Planning Mission Statement, pg. 1).

The agency is effective in presenting a concerned, caring image to the public, and I believe that the agency's leadership believes that the agency provides some of the best care and "normalized programming" in the United States. Holding such a position and
taking such pride in one's agency and its employees is commendable. However, not all employees, including a few management-level employees, agreed with such affirmative convictions. For example, while discussing the important role played by the tenets of normalization within the agency, one management-level person stated,

At an administrative level, it drives most, if not all, decisions on program and staff issues. In discussion, when reviewing client program issues--it is always paramount. It drives the service philosophy--BUT! What is normal? We make a good effort, but not good enough. It is accomplished only as good as the supervisors are committed (Respondent M-3, 1993).

We can't normalize. We must assist in developing the individual's potential. However, rules that drive funds often are directed to least expensive options. This pushes (the agency) toward group training, living, and community integration. That's not normal (Respondent M-3, 1993).

Another high-ranking management-level employee's comments present one example of how the basic tenets of normalization are not easily translated into services and social reality at the direct-care level. She even went as far as to suggest that the agency provided only "lip service" to the entire process, again, suggesting that public image and direct-care reality are some how unassociated. She commented,

Normalization is just another buzz word for the agency. Certainly, everyone within the agency wants to think that the agency is above reproach in its dealings with its consumers. That everyone fights for their client's rights. The actuality is "no new is good news." The status quo is perfectly acceptable, meaning that if your residents or direct-care staff are not causing problems, then management people are doing a good job. If you were to ask the powers that be, however, you would be told that there isn't an agency in the state that does more to train, motivate, or promote their consumers (Respondent M-1, 1993).

I think that within the agency the term normalization is misunderstood, misused and the direct-care employees, those who hold the key to the consumers' success, are often misinformed as to their responsibilities in the whole process (Respondent M-1, 1993).
Undeniably, these claims presented a different image of the agency when compared to the image the agency wished to confer upon itself. For example, clearly the comments about the tendency for the agency's leaders to discourage the transmission of "bad news," no matter who the delivery person may be, is self-destructive, non-productive, and demonstrates very serious flaws in leadership. This pressure to maintain the status quo also appears to place those who supervise in a difficult position, to not present problems to those above them, and to somehow manage to protect both their subordinates and consumers. One management-level employee described his frustration over fighting against the agency's leadership for one of his consumer's rights:

I have suggested that there are people in some of the houses I am responsible for who would benefit from a smaller, quieter living environment, and all of my requests have been "kabashed." (For what reason?) Past history within the agency. I mean, I was told that "we know the client better," or "this client has been here forever, we know him better." (They claimed they knew the consumer better than you did?) Yup. They put me in my place with that idea (Respondent M-11, 1993).

I think that the biggest problem with normalization for clients in this agency is the fact that those folks who are telling the supervisory staff where people should live are out of touch with where the clients really are [with their training] (Respondent M-11, 1993).

And when it came to the actual process of normalizing:

We should be using every talented skill we have as staff to hone clients' skills. I see warehousing of clients and I see skills not being practiced because people are not being moved and also because, quite honestly, some of the housing staff just don't get it (Respondent, M-11, 1993).

Options aren't given, choices aren't given. I hate to say this, but I see a lot of staff walking around who come to work carrying a lot of excess baggage from home. The agency is going to have to face facts and start dealing with the fact that staff get burnt out easily. I know of one person who was treated poorly by the agency, not because she was a horrible employee, but because
the agency didn't know how to work with a person who was getting burnt out (Respondent M-11, 1993).

He was called in, told to sit down and shut up. He was told to "knock off his shit." That kind of stuff...very inappropriate statements. He was told to knock of his crap, to sit down and just listen and this was the way things were going to be. I have personally witnessed [name of management staff] treating direct-care staff like that (Respondent M-11, 1993).

You know. If we're trying to normalize clients, we'd better start by treating our staff right. There is such fear of retribution [among staff] (Respondent M-11, 1993).

Even direct-care staff notice discrepancies between what they consider as a programming ideal and what really takes place. The following passages are a collection of comments from those who work with the consumers on a daily basis, and depict social reality from their perspective. One RPM assistant stated,

I do want to stress that even though our main goal is to serve our clients, we, as direct-care staff, need to be treated a whole lot better than we are by upper-management. The decisions that are made by upper-management have made a lot of us direct-care staff feel "something less than human." In the short time I have been here, the moral has gone so low. When this happens, it really shows on the staff and our clients do pick up on it (Respondent S-39, 1993).

An aide summarized his feeling as follows:

Sometimes I feel self-conscious about sharing concerns with my immediate supervisor. I don't feel like I have her complete promise of confidentiality. In other words, I feel she will tell others about my concerns. She has proven herself to be a gossip in the past (Respondent S-25, 1993).

One RPM drew attention to the fact that what is often done at the direct-care level is not always based upon cliental need, but what might be consider a quick answer or fix:

The agency should arrange case loads and individuals responsibility in a manner that allows decisions to be made based on all the facts considered rather than just for the sake of expediency. The agency
needs to assure that stated objectives and consumer programs are in fact effectively implemented and carried out (Respondent, S-8, 1993).

Finally, another RPM offers insight into potential shortcomings within the agency:

The community needs to be better informed and the agency needs to take on a more active role as an advocate. Normalization can only occur in a community where all are accepted as normal. Given the financial constraints suffered by consumers, options and choices are very limited. Individual Program Plans need to be geared more to individual needs which will make a person’s quality of life as high a priority as rehabilitating them is in this agency (Respondent S-12, 1993).

A Lack of Accountability

One thing that struck me as odd is that the agency has no system of accountability. I found no evidence of any internal system that would enable the agency’s leadership to come to the conclusion that their agency wasn’t doing what they believed it was doing. This fact really does add credence to the notion that within the agency, "no news is good news." If no accountability is requested, then there is no way of judging if the day-to-day operational information the leadership receives is valid. Also, having no system of accountability places undue stress on lower-level management personnel who must decide what information gets passed along, how it is phrased, who should receive it and when. Because of this type of system, problems may remain hidden and not dealt with accordingly, and, over time, serious consequences may result from inactivity. In fact, the agency and its employees may develop an attitude that precludes some consumers from achieving their dreams of total independence.

For example, when I asked one management-level person whether or not the agency had a system from which to judge success, the person responded that such things were
based on client satisfaction. When asked how the concept of client satisfaction was measured, the employee responded that it was measured through judging the community’s inability to separate the agency’s clients from the crowd or the staff. I didn’t have the heart to carry the discussion further. The management-level person did state that while the agency did not have a formal tool as of yet, it would in the near future, and that certainly the clients would have to be asked for input. The inherent problem in this situation is that without such a measure, it is difficult, if not impossible, to reliability judge whether or not anyone is accomplishing the over-arching goals of the agency. In effect, not having a formal measure to rely on allows the agency’s leadership to form any opinion they really desire. Who, or better, what is to contradict them in their assessment?
I differentiated between "internal" and "external" obstacles in my study. Internal obstacles to normalization accounted for a variety of impediments at the individual and organizational levels of analysis. These included obstacles that originated through interaction between different staff and between staff and the consumers whom they serve, as well as scrutinizing the bureaucratic structure of the agency. In contrast, I operationalized external obstacles as entities that originated outside of the agency and that could be located at all three levels of analyses. I asked employees to list various systemic features which, in their opinion, block efforts to normalize their consumers. I believed that the results would not only demonstrate that agency staff understand the concept of normalization, but, more importantly, that these data would act as an early indicator for whether or not such obstacles might exist. Following a brief review of those findings, I turn to specific areas of concern.

I wanted to begin the discussion of obstacles to the normalization process with an examination of the topic from the vantage point of the staff. As part of the general questionnaire, respondents were asked to identify anything that they believed was an obstacle to the process by actually listing such things. The information displayed in Table 2 is representative of all staff and contains sufficient data to find that many of the agency's residential staff were familiar with various obstacles. I believe that their responses were more an indication of the amount and types of frustration they had
actually experienced rather than responses based on some type of speculation. It is interesting to note that while some may feel that societal obstacles are more important, since they supersede the others, respondents offered many more "organizational" obstacles than either individual or societal.

A few of the responses listed under "Organizational Structure" could easily have been placed under "Individual Attributes." I decided to group them as presented simply because that while staff behaviors toward their consumers are certainly individual and take place at the micro-level of analysis, I believe that their existence directs attention to problems within the agency's organizational structure. For example, staff reported that lack of employee motivation toward working with consumers was an obstacle. If such situations did exist, then I viewed their existence, in part, as some type of systemic failure associated with the agency's structure (e.g., lack of training, inadequate supervision, poor use of agency sanctions, faulty leadership, and so forth), rather than considering them solely as manifestations of flawed psychological characteristics.

Thus, from their perspective, employees reported that a wide range of obstacles to normalization were present. Although I did not ask them to report the frequency or duration of these manifestations, these data, none-the-less, provided insight into the complexities involved in the metamorphic relationship between normalization in theory and in practice. For the first time, an indication was given that strongly suggested that differences between agency image "spin-doctoring" and social reality existed.
Table 2. Obstacles to the Normalization Process as Reported by Agency Staff

Question: List ways your residents' efforts to become normalized are blocked? That is, do you see any obstacles to the normalization process?

Personal Attributes:
1. A person's physical disabilities.
2. A person's emotional disabilities.
3. A person's learning abilities.
5. A person's behavioral problems.
6. A person's lack of motivation.

Organizational Structure:
1. Providing to many "disabled only" social activities.
2. Parents and other advocates allowed to have negative influence in process.
3. Staff lacking proper motivation toward working with consumers.
4. Staff generating unrealistic goals for consumers.
5. Lack of continuity between staff when it comes to consumer programming.
6. Having too many rules/guidelines within the residential settings.
7. Agency not being flexible enough to handle "odd" consumer cases.
8. Too many programs and too much emphasis on them.
9. Staff forgetting consumers are disabled - unrealistic expectations.
10. Large group home settings are not normalizing.
11. Working conditions are bad, lack of income and job benefits.
12. Agency chases funding and is driven by it rather than consumer interests.
13. Staff can become too "protective" of consumers and hold them back.
14. Staff look at their job as a "9-5" situation; lack of enthusiasm.

Societal Structure:
1. Too much social prejudice directed toward individuals with disabilities.
2. Media needs to be more careful in articles about persons with disabilities.
3. A general lack of suitable employment opportunities.
4. System funding changes too quickly for housing and related programs.
5. Transportation system has severe limits which impact consumers' options.
6. Lack of interaction between disabled and "normal" population leads to social isolation.
7. Perpetuation of myths through stories, jokes, and other sources of stigmatizing.
As mentioned earlier under the methods chapter, each of the twelve sub-scales contained four statements on which respondents score themselves. Using SPSS/PC+ (Norusis, 1988), individual ratings were selected and added to compute the sub-scale scores. These scores are presented in Table 3. Rather than showing scores from each respondent, sub-scale scoring is represented in percentages, showing the placement of respondents into either a "high" or "low" group. Assignment to one of the groups was based on individual cumulative scores on each sub-scale (low score to 12.5 = low group, all others = high group). The dividing criterion, 12.5, was the halfway point between the lowest score possible of five and the highest score of 20. In their original form, the CRPOS' sub-scales have a "most desired" direction in which favorable responses go. For example, of the twelve sub-scales, eight stipulated that favorable employee responses (favorable attitudes) should fall into the high group to be most favorable. In contrast, the favorable responses in four of the sub-scales was the low category. In order to simplify group scoring, I recoded those sub-scales in which the most desired group was the low group so that the most desired group (the most favorable attitude) was the high group classification for all sub-scales.

With respect to the CRPOS, individuals with cumulative sub-scale scores above 12.5 were placed into the high (positive attitude) group. Based on these results, a majority of respondents' reported having positive attitudes on 9 out of 12 of the sub-scale scores. Those areas in which a majority of staff were placed into the less preferred group included: a) Push to Accelerate, b) Negative Ward Management, and c) Job Insecurity.
Table 3. Staff Attitudes Toward Work, The Agency, and Their Consumers (N=63).

<table>
<thead>
<tr>
<th>Sub-Scale Item</th>
<th>N in Low / High Group</th>
<th>% in Low / High Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Negative Physical Care</td>
<td>28 / 35</td>
<td>45% / 55%</td>
</tr>
<tr>
<td>2. Job Rejection</td>
<td>16 / 47</td>
<td>25% / 75%</td>
</tr>
<tr>
<td>3. Push to Accelerate</td>
<td>32 / 31</td>
<td>51% / 49%</td>
</tr>
<tr>
<td>4. Negative Ward Management</td>
<td>44 / 19</td>
<td>70% / 30%</td>
</tr>
<tr>
<td>5. Comradeship</td>
<td>3 / 60</td>
<td>8% / 92%</td>
</tr>
<tr>
<td>6. Job Insecurity</td>
<td>35 / 28</td>
<td>56% / 44%</td>
</tr>
<tr>
<td>7. Institutional Identification</td>
<td>20 / 43</td>
<td>32% / 68%</td>
</tr>
<tr>
<td>8. Encourage Verbalization</td>
<td>3 / 60</td>
<td>5% / 95%</td>
</tr>
<tr>
<td>9. Irritability</td>
<td>31 / 32</td>
<td>49% / 51%</td>
</tr>
<tr>
<td>10. Equality</td>
<td>6 / 57</td>
<td>10% / 90%</td>
</tr>
<tr>
<td>11. Strictness</td>
<td>22 / 41</td>
<td>35% / 65%</td>
</tr>
<tr>
<td>12. Fostering Dependence</td>
<td>4 / 59</td>
<td>11% / 89%</td>
</tr>
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Since the purpose of using the CRPOS was descriptive in nature, (i.e., discovering into which of the two groups a majority of respondents fell), I did not feel that testing for significant differences between group means was appropriate. In addition, my data did not meet the minimum requirement of a random sampling, and further, group assignments were established by examining the results on only one variable (cumulative scores on each sub-scale) and were not compared to any independent variable (e.g., position in agency). I now turn toward brief examinations of the three sub-scales in which a majority of the respondents indicated harboring negative attitudes.

Pushing Consumers Too Fast Toward Normalization

With respect to the first sub-scale, a small majority of respondents (51% to 49%) reported having attitudes that would suggest that staff feel consumers should wean themselves from depending upon staff as soon as possible, emotionally and otherwise. In essence, staff who hold similar attitudes may feel that consumers should be pushed toward independence and to develop in the shortest time possible. There is a danger in following this mind set when it comes to training and evaluation. One RPM discussed the outcome of pushing consumers too fast toward normalization:

Pushing clients too soon depends on the clients. Depends on their temperament. Staff keep people who are nice and push those who are bad. They want to get rid of them. (Why?) Staff don't want to deal with them. Its easier to move [them] to a higher level than to move them backwards. (How is that done?) Through assessments. You give them higher marks. You say things like, "He's getting better now." Make everything you say positive (Respondent S-59, 1993).
The agency wants us to push clients out, but most clients don't know about family. For many of them it's the first time they have a friend [the staff]. There's nothing negative in that, but don't make them too dependent. It's a balancing act (Respondent S-59, 1993).

Thus, pushing a consumer toward independence is considered a positive thing if done correctly. However, there does appear to be a negative side to the process. For example, if consumers are not evaluated properly, staff can set them up for failure. I know of cases where consumers had to be pulled back and placed into more structured residential environments because staff had improperly measured their skill levels. As the employee below pointed out, since management-level employees normally make the decision to move consumers onward, reversals of such decisions can be rather difficult to accomplish and very troublesome to accept:

Once supervisors and directors make a decision to move people it's a done deal. They don't want to admit to mistakes and they just expect staff to work with their mistakes. It's not fair for the client. Staff need to feel important. I have suggested ideas to various people and felt like an intruder for doing so. The idea may not be following a prescribed pattern and, therefore, it was discounted. There's just too much ego stuff going on at [name of agency] for me (Respondent S-25, 1993).

Simply stated, the problem is that when emphasis is placed on accelerated promotion of skill training, there may be a tendency to over-rate consumers on skill levels. Such pressures can originate from funding sources (e.g., state or county personnel who may wish to make room for more needy persons) or even from well-intentioned, but over zealous, employees who may associate personal work performance levels with consumer advancement. Thus, some consumers may be put into situations for which they are not ready and, in many cases, with much less support from the agency. Such situations
would seem to have a high probability for failure. Sadly, it has been my experience that agency employees often attribute such failures to some character flaw in the consumers rather than affixing fault onto the system which relocated them into precarious residential environments in the first place.

Another reason why some consumers have been over-rated is simply that staff did not like to work with them. In essence, they were troublesome. It is true that some consumers can be difficult to work with, especially during initial transition periods during which time they are adjusting to new demands and situations. Often when consumers experience more freedom and new opportunities in which to express individuality, they often "over-play" their hands by pushing the limits of house guidelines, stepping over prescribed social boundaries, and testing the staff's limitations and nerves. I know that in some cases, staff have actively worked toward removing difficult consumers by over-rating their skills. This practice amounts to what some in the agency refer to as "dumping." Ultimately, consumers can be victimized by the system that expects and demands that they perform at skill levels they are suppose to possess, but in reality, do so only on paper. Another RPM also talked about the practice of over-rating and moving people on before they were ready:

Yea, it happens sometimes. Some staff always over-rate the people they want to get rid of and then they have real problems. One woman was moved out on her own simply because staff couldn't stand her ways. She drove the staff crazy so they got rid of her; she was "mental." There's no way she's ready to be on her own, even now. Another woman was moved out into her own apartment before she was ready and there was serious problems with respect to her safety and security. She wasn't matured in the area of good judgment with strangers (Respondent S-01, 1993).
It's kind of sad because harm can be done to clients. I know of two cases in which residents were brought back into the system after living on their own for a while. It was finally discovered that one gentlemen was not eating, cooking, and cleaning his apartment. To the point that it was effecting his health. Another woman had such a bad experience living on her own that now she refuses to leave her apartment. She really failed bad. She had a terrible experience and now she suffers because of mistakes made by staff (Respondent S-01, 1993).

When asked what was behind such bad assessment procedures, the RPM said,

There seems to be an ego problem in the agency. What I mean by that is simply that supervisors and others who really don't work with these people on a daily basis - or in situations where they can observe and learn about the residents - are the ones responsible for assessing and determining when someone is ready to be moved on. This doesn't make much sense to me. First, direct-care staff should be involved in the process, and I guess they are to some extent. However, I've never been asked for my straight out opinion when it came to moving a resident on (Respondent S-01, 1993).

Second, I don't think the agency really wants the supervisors to involve direct-care staff in such major decisions. The agency holds these long meetings with upper-up employees who decide the fate of persons they normally know very little about. This is why they have so many failures in [name of agency] (Respondent S-01, 1993).

Finally, one account is offered which demonstrates how ineffective, and even counter-productive, management-level employees can be when they become engaged in decisions about consumers with whom they have only limited daily contact. Specifically, three staff persons had worked for over two years in assisting a consumer who had a history of severe compulsive-obsessive disorder behaviors. One of their tasks was to simply work with the consumer in hopes of reducing some of these compulsive behaviors, a couple of which included covering her bedroom walls, door, and furniture with personal notes and reminders, and telephoning her direct-care staff and the agency several
times each hour in order to ask them the same questions, even when she had already received her answer. One specific targeted behavior that the staff had been successful at reducing was her use of the telephone for contacting staff and the agency.

Recently, there was an occasion during which a management-level employee was told by this consumer that she had been asked by her staff to not call the agency with her "concerns," but, rather, that she should contact only her direct-care staff. After hearing this, and before discussing the situation with any of the direct-care staff involved, the management-level employee told the consumer that she was free to call the agency anytime she wanted to, and, further, that she didn't have to depend solely upon staff for her concerns. Within 24 hours, the consumer had approached her direct-care staff no less than 23 times confused and very anxious over when she should depend upon her direct-care staff and when she should call the agency. In addition, the consumer's direct-care staff had received several calls from the agency's secretaries who asked the staff to intervene and stop the consumer from calling the agency so frequently. According to agency secretaries, this consumer kept calling for the management-level person who told her to call the agency in order to have the term "concern" defined for her. Thus, a very inappropriate behavior pattern that had taken over two years to reduce was started again within a matter of seconds by a single management-level employee who didn't have a clue about what she was involved in, or enough common sense to conclude that perhaps she should discuss programming situations with the consumer's staff prior to countermanding approved instructions her direct-care staff had presented to her as part of an IPP.
Paperwork and Picking Up After Others

The second item on which a majority of respondents found themselves in the less preferred group was that concerning negative ward management. This item asked respondents to remark on residential tasks involving both administration and housekeeping. A clear majority of staff (70% to 30%) indicated that they felt that there was clearly too much demanded of them in these areas. For example, a majority of staff felt that housekeeping tasks and record keeping were some of the most boring tasks for which they were responsible. In addition, they felt that paperwork, in general, was pure drudgery and that the agency should take steps to relieve them of unnecessary tasks.

According to one RPM:

The staff don't like it [paperwork], especially when you deal with clients on a daily basis. They [the staff] get "fried." Many staff are intimidated by all the paperwork. What happens when paperwork isn't done right or on time is bad. Clients may lose money. IPP [individual program plans] are not done on time. Paperwork is often backdated and they [staff] cheat on coding a month later. Staff really don't do assessments well. They don't ask the clients for input. Staff just guess at things and say "yes" or "no." You just mark them down because paperwork has to be done (Respondent S-02, 1993).

One possible explanation for why staff feel negative toward the idea of performing this type of work is that such work might unnecessarily interfere with work they consider more important or more beneficial, i.e., interaction and consumer programming.

Another reason for why some staff may feel irritated is that often they feel that work is beneath them, perhaps more suitable for aides and assistants. Sadly, such work needs to be done while showing respect and dignity to those who require assistance. One RPM assistant indicated the disgust and irritability with which she approached her job when it
came to cleaning up after consumers:

I hate that part of my job. I just hate it! I think the sickest thing I had to do was clean up a bunch of turds that one client left floating in his bathtub. I mean the houseparent told this guy to cool off and take a warm bath cause he was upset. Well, he went in the bathroom, got into the tub, and took a big shit. I was so mad I wanted to kill the guy. And then my houseparent told me I had to clean it up. I wanted to tell him to go get fucked! I can tell you I gave it to that guy [the consumer] after that. He hasn't ever pulled that one again. He takes showers now (Respondent H-1, 1993).

Job Insecurity

The final area in which a majority of respondents placed themselves into the low group was that which concerned job insecurity. According to Table 3, 56 percent of the respondents felt insecure about their work. In addition, they reported that when things do not go right the blame was often placed at their feet, or they are blamed for things that are of little consequence and for things that were not their fault. In addition, a majority of staff reported that they often worried about performing in a way that would cause them to forfeit their jobs. One person who had recently left the agency captured what he felt were general feelings staff held about job security:

Four years ago, in [name of the agency] there were no worries. It was safe and no one really worried. Now, the rules are changing. There's more expectations. It used to be like a "mom and pop" organization, and now it has grown. Money is now a problem. Loyalty is going out the window. People don't care anymore. Staff work only assigned times. They are doing less maintenance because they think it is the agency's house now and not their home (Former Employee, 1993).

People are bitching a lot. Management is lying to staff about the future [what it holds for them]. One week it was like this and the next week its something else. Actually, many already know that the agency began hiring new employees for less money. They started to pay new residents program managers as assistants for doing the same job. What I didn't like
was that I think the agency purposely set staff against staff for the jobs that will be left behind. I didn't want to deal with this stuff. Things were bad and will only get worse for those still working as direct-care. They better watch their butts is all I can say. Right now is a bad time and staff are on edge. A real bad time (Former Employee, 1993).

With respect to job insecurity, there is a longstanding tradition in the human service field to blame the direct-care staff for failures of the system. Since they are the lowest paid, have the less glamorous job - albeit the most important according to the agency's Director - and are powerless when it comes to job status, this is not a surprise. I discovered in my talks with many persons that there is an attitude among employees that the agency is quick to reprimand direct-care staff and somewhat reluctant to do the same when it comes to management-level employees. During an interview, one RPM assistant summarized staff frustrations and fears this way:

I know for a fact that supervisors get away with a lot. For one thing, they even get hired for the job when they aren't qualified. Some didn't even have the required experience the job required and they got hired over persons who were better qualified. I can't go into a lot of detail, but let me say this. I know that some supervisors and higher-ups that have done some really bad things and have not gotten in trouble (Respondent H-11, 1993).

I mean things like messing up big time on checking in, charting and medication delivery, getting inconsistent when it comes to writing-up their workers, they take off during the work day for no reason. I mean they just plain leave their office and don't come back for the day. It's also kind of a joke that the company's supervisors are a waste of time and money since direct-care staff really know what's going on (Respondent H-11, 1993).

If it were up to me, I'd do away with the whole lot and start from square one. It's kind of freaky when you know that any company in [state] can fire you for no reason what-so-ever. At this agency, there's suppose to be an "open door policy" with the directors, but everyone knows they don't want to hear our problems. It's well known that those who talk openly and honestly with them end up on the losing end of things (Respondent H-11, 1993).
Management, Direct-care Staff Relationships, and Job Insecurity

Directly related to issue of job insecurity is the fact that good working relationships between direct-care staff and management-level employees are important to the success of the agency and consumers, alike. The amount of stress that direct-care staff encounter during a workday can be extremely high. The frustration and anger stemming from poor morale can lead workers toward apathetic feelings and, subsequently, into poor work performance and bad attitudes toward their consumers. Since management-level employees present many messages to their staff with words and actions, it is of some import that they appear caring, concerned, and sympathetic whenever working together. When this doesn't happen, direct-care workers can quickly feel like they are just "hanging out there," alienated without support. There were quite a few reports from direct-care staff with respect to the treatment they either perceived or received from those filling supervisory roles.

For example, recently I was engaged in conversation with a non-agency person when the person asked if I knew "so-and-so" from the agency. I told him that I did know of the person. In fact, the person was one of the agency's program directors. He then commented that this program director had told him that she just hated having to work with direct-care "pee-ons." Likewise, one agency supervisor was discussing the fact that direct-care staff could not have been responsible for preparing a document that had arrived at the agency headquarters which was critical of the agency. After apologizing in advance to the direct-care staff in her presence, the supervisor added the observation that
the letter could not have been penned by direct-care staff because direct-care staff were just "not smart enough to have written the document."

When employees were asked about conditions within the agency that they felt were bad and were in need of change, many direct-care staff seemed to indicate that a general lack of respect and much distrust best described the relationship between management and direct-care staff. A few of the concerns expressed by these staff include the following:

They (supervisors) should listen to us. There's way too much breaking of rules by the supervisors (Respondent H-4, 1993).

Lower paid staff always get dumped on. Many times it's the supervisors who are at fault. They don't get in trouble. People on top don't know what's happening down with the clients (Respondent S-04, 1993).

Poor housing staff should be fired. Incompetent staff trained or fired. More team efforts put into action. Increase morale among staff - praise and compliment hard work and good efforts. When staff are praised and complimented they can then pass those good feelings and attitudes on (Respondent S-56, 1993).

Staff needs to be rewarded more for the work they do. Not just RPMs, but everyone. I see that supervisors need to remember that they need weekends and time away from work, and so do we. A day off is a day off. If you're not on the schedule to work this day, you shouldn't be expected to attend classes, etc. That's why you hear "burn out." I've been called upon on my day off to attend a lot of things. Where do we separate work from home? I work to live, not live to work (Respondent S-48, 1993).

We need much more involvement of the consumers. We need to involve more consumers in teaching each other. We need to ask for their opinions. I believe we need to lose the egos of the "higher ups" in the agency (Respondent S-46, 1993).

Supervisors need to listen to staff and take them seriously. RPMs and aides are the ones who know the clients best and know what their needs are (Respondent S-44, 1993).
I do want to stress that even though our main goal is to serve our clients, we, as direct-care staff, need to be treated a whole lot better than we are by upper management. The decisions that are made by upper management have made a lot of us direct-care staff feel (like) "something less than human." In the short time that I've been here, their morale has gone so low.....and clients do pick up on it (Respondent S-39, 1993).

And finally:

Supervisors don't have a clue for the most part. They rarely visit their homes even after we were told they would start doing this. Makes a person think that those in charge really aren't in charge of much. The supervisors also get hired when they shouldn't be. I know of two cases where the persons hired weren't qualified. The company had to lower their standards in each case. They didn't have the experience the position required, but those up there made the decision to hire them. I wonder who else could have applied for those positions if they let everyone know about the changes (Respondent S-01, 1993).

You could do away with all of the supervisors and the company would run a hell of a lot better. We really don't need them, but they sure wouldn't agree with that comment. Too many egos are involved here. And for no reason. They are the laziest bunch of prima donnas I have ever worked with. Shouldn't hold your breath though because things don't work that way. We're the ones who are always wrong. What do you expect? They hang together (Respondent S-01, 1993).

One of the most alarming outcomes concerning rifts between direct-care staff and management had to do with emergency medical procedures. An important concern for both the agency and consumers who live in their own apartments has to do with reporting and taking care of emergency situations. Since these apartments are scattered around the city, one apartment complex was designated as a clearing house for consumers to report emergency situations. However, during conversation with one RPM, it became quite clear that the arrangement was not the best alternative for many consumers, and, in at least one case, proved to be dreadfully inadequate:
My [name of home] is situated near several consumers who live in their own apartments. One day, I received a telephone call from one of these consumers. She was very upset, almost in shock over the fact that she had cut herself while using a kitchen knife. She told me that she called the agency's emergency number like she was suppose to, but that it had been 40 minutes ago and no response had come yet (Respondent S-70, 1993).

I told the woman to come over to my office and I would assist her. When she arrived I was shocked to see the amount of blood. It was all over. I immediately took care of the situation. It was clear that the consumer was close to going into shock. The system had failed horribly. This was not the first time I had offered assistance to consumers who live next door to me. It seems to me that the system could be set up better. I expressed this concern to the supervisor and program director in charge of those consumers who live in their own apartments (Respondent S-70, 1993).

I mentioned that I would prefer to have my many consumers contact group home staff who worked just a few blocks away if there was an emergency situation and I or other staff members were not around to assist them. It just makes more sense to have a reactive force within one minute rather than calling staff who live a good thirty minutes across town. I quickly discovered that my request was not even going to be seriously entertained, not for one second (Respondent S-70, 1993).

Another part of the reason this rift exists can be attributed to manner in which supervisory level persons perform their jobs and the supervisory style many have adopted. There is a perception that many, if not all, of the supervisory personnel spend most of their time at the agency headquarters rather than in the homes with the staff and consumers. By default, this makes them dependent upon their staff to inform them when problems or other situations arise. However, with such dependency comes the need to look dependent, and, if dependent, then perhaps ignorant and less effective in the eyes of those whom they supervise. One manner supervisors may react to this is to become even more withdrawn from the situation, blaming their absence in their homes on excessive
paperwork and other demands. However, there may be some truth to these hypothetical explanations. One management level person discussed the pressures his group feels, stating:

It's really a salt mine in the agency. I've talked with co-workers who kinda have the same impression I have. We all feel that our collective spirit has been killed. We all feel that we were just keeping our heads above the water and now we're suffering more headaches and more work and more demands on our time then we've ever experienced. The work continues to pile up and the demands continue to grow. People in my line of work in this agency are scared as hell. They're scared shitless (Respondent M-15, 1993).

They don't want to be in [work] their houses. They like working at the agency's headquarters. My personal philosophy is that a co-worker can only follow as well as a leader leads. I don't think that we have the kind of leadership in this agency that is easy to follow (Respondent M-15, 1993).

Why such a gap exists between management and direct-care workers in the agency is certainly a matter of interest given the impact it can have on the mission goals of the agency. Many items seem to be at play which act to promote such a conflict-oriented environment. First, and foremost, there is the issue of power. Management has it, and the direct-care staff do not. In many organizations, management appears bent on demonstrating this fact at every opportunity. Interestingly, the data also suggest that serious, power-based problems exists at the management level. One management person described how the activities of certain powermongers within management have had negative impact upon the normalization process. In particular, when leaders use coercive power as the basis for leadership, subordinates grow reluctant to share information, even when they know that it is important. He described the situation like this:

We're not really normalizing anyone. We're saying we're doing all this stuff, but if you'd go in the residences and look, our clients wouldn't be doing it
or even know what their programming is. If I could change anything, I'd make it so that [name of executive director] and [director of residential services (DRS)] had to visit residences so many hours per week (Respondent M-1, 1993).

They don't because they don't have to. It's like there's this code of conduct for each level in this agency. There is the management level where [name of DRS] says this what thou shalt and shalt not do. It's intimidation. I don't think we take or give feedback/criticism freely. We are very guarded as a team (Respondent M-1, 1993).

There was an issue I wanted to bring up at a management meeting a few weeks ago, but I took one look at the director's face and knew that I would be in trouble. She didn't want to hear it. They seldom do. There's a lot of things I would love to bring up, and there are many things I would like to challenge because I know they are wrong, but I don't (Respondent M-1, 1993).

The DRS says she has an open door policy; she makes a point of stressing this and even puts it in writing. I know very few people who have done it. I don't think she intends to present an intimidating presence, but there is little doubt about her power-tripping. She is defensive and challenging (Respondent M-1, 1993).

I know a few persons who have stated their honest positions and are now paying for it. They just made the mistake of believing that there really is an open door policy and opened their mouths. There is such fear of retribution in the agency. It is always do as I say and not as I do. But there is a protected species (Respondent M-1, 1993).

There are "favorites" within the residential services department. I kind of equate it to Star Trek. We have our Captain Kirk, his bridge crew and then we have the Klangons. These people can be summed up as those who be, those who wanna be, and those who couldn't give a shit less. I don't think anyone in management tells the whole truth (Respondent M-1, 1993).

Intimidation is one method of maintaining the power status quo in an organization, but it is certainly not the best method of establishing and maintaining effective, long-term leadership. What the management person was describing above is referred to as
"collusive behavior" (Butler, 1987). It is a method through which persons decide to cooperate with others consciously in order to reinforce dominant attitudes, values, and opinions. It is, in effect, related to the idea of "group think" (Janis, 1982). In the agency, it appears that most members of the management team suppress their true feelings and say only positive things in response to questions and remarks made by the agency's leaders. That is, everyone involved knows the game and how it is to be played.

Staff Irritability

While pushing consumers to develop, negative ward management, and job insecurity were the only three areas in which a majority of respondents found themselves in the less preferred direction, "Irritability" was another area in which the respondents almost split evenly (49% in the less preferred group, 51% in the preferred group). The important thing to note is that almost half of the respondents felt that "blowing their tops" was justifiable at times, and that clients often got on staff's nerves after being with them all day long. Likewise, these staff reported feeling that they could not stand their group of consumers. I know how irritable staff can actually become due to the stress of their jobs and because some staff are not well suited for work with consumers in residential settings. One RPM assistant presented a story in which an aide worked around a situation in which she felt the consumer was "getting away with too much." The aide apparently got irritated and then manipulated the consumer and the consumer's environment to produce the desired results, i.e., irritability led to excessive social control and negative consequences for the consumer. The aide reported:
I hated taking Mary (not the consumer's real name) to the grocery store because she's a pain. Lately, I set her up by telling her she can't buy this or that and that really gets her mad. So, she makes a big stink in the store and I threaten to leave her alone in there and the clerks get all red and things. Finally, last week, I told her she couldn't buy pop and she got mad in the store. It was so bad that the store manager called my boss and asked that Mary not come back in for a while. My boss decided that I could shop for Mary alone and now I don't have to take her no more. (Respondent S-2, 1993).

From the above passage, it is easy to see why irritability is such an important item to examine. This is of concern because the stage for abuse and excessive social control and manipulation could be set by harboring such attitudes. Such abuse can take place in many ways and in many settings. One RPM responsible for a eleven consumers at a group home reported that frustration often builds when out in public, especially when shopping with a few consumers at one time:

...when I take my consumers shopping I don't always give them their choices or the opportunity to really shop for themselves. I don't have the time for that. I pick out two dresses and ask them which one they like the best and they buy it. There have been times when I also threatened to cut the shopping trip short when they started becoming difficult. That makes them fall in line in an instant. God, it's tough to keep your cool. They push your buttons until you blow and push back. Then they get with the program (Respondent H-9, 1993).

Taken together, these data do show that while normalization may be the official policy of the agency, implementing the tenets of the service philosophy may be difficult, especially given some of the general attitudes held by staff. In addition, the topic of job insecurity is considered very important when it comes to job performance, and, ultimately, the success the agency experiences toward normalizing its consumers. Thus, these data demonstrated that there may be a need for real concern in the areas of staff
morale and attitudes that deal with respectful treatment of the consumers. But this is only one part of the picture. The next area to be examined focuses on an extension of staff attitudes that focuses on feelings about the sexuality of individuals with developmental disabilities.

Staff Attitudes About The Sexual Behavior of the Disabled

Rather than reporting individual composite scores, Table 4 represents interests in understanding general group trends with respect to attitudes toward the sexuality of consumers. Thus, scores on the Sexuality and the Mentally Retarded Attitude Inventory (SMRAI) were placed along a continuum and divided into one-fourths. Scores could range from a low of 25, reflecting a very liberal attitude, to 100, the most conservative score possible. Dividing points were established by adding 18.75 points beginning with the lowest possible score of 25 which produced the first cutoff point at 43.75, the second at 62.50, the third at 81.25, and the fourth category filled with any score above 82.15.

The findings were somewhat surprising. Based on these groupings, 19 percent of the respondents reported that they held positive attitudes toward the sexuality of the type of persons with whom they work. Seven point nine percent felt "very positive" about the issues, while 11.1 percent were placed in the "positive" group. The most interesting finding is that the vast majority of respondents reported having negative attitudes toward the issue of sexuality of individuals with developmental disabilities. A rather significant 60.4 percent reported having negative attitudes, with 20.6 reported having very negative attitudes about the topic.
When controlling for staff status level among the respondents, some rather surprising statistics develop. Among the direct-care staff, residential aides were split between liberal and conservative scores. Among residence program manager assistants, one assistant scored in the positive group while 5 scored in the negative group. Finally, among residence program managers, 17 percent scored in the positive group and 83 percent scored in the negative group. All eight supervisors scored in the negative group, as did all the directors. Finally, of the five counselors taking part in my study, only one scored in the positive group. Thus, of those who reported themselves as "liberal-minded" on the topic of the sexuality of their consumers, only one was not a direct-care provider.

One of the interesting findings to come from this analysis is that while the agency guarantees its consumers the right to sexual freedom (with some restrictions), a majority of agency staff hold attitudes that stand in contrast to the agency's position. If members of the policy-forming and supervisory arm of the agency hold negative feelings about the idea of sexual expression among their consumers, it may point to another potential obstacles toward normalizing consumers. Again, while there is no connection made between attitude and behavior, certainly it may provide insight into the need for increased in-service training with respect to the consumers' rights to engage in sexual behavior if so elected.

I have witnessed occasions during which manifestations of staff behaviors where over controlling of sexual situations have taken place, especially when it involved moderate functioning consumers. During many social gatherings involving consumers, staff have redirected couples and asked them to stop their public displays of affection. Sadly, these
occasions were among the few times when consumers were able to get together with their boyfriends and girlfriends and they were merely making the most of the opportunities. Rather than being allowed to roam the area to find more private surroundings, staff ensured that all consumers stayed in one general area. Thus, for boyfriends and girlfriends it was impossible to be discrete about their affections. Staff were, in a sense, providing their consumers with two options - show their affections in public, or do not show them at all. During these events, staff were often overheard commenting on how ugly and disgusting their consumers looked when it came to kissing in public. Many staff even made jokes about the fact that their consumers were showing affection. This was a very telling indicator of the double-standard that persists among human service professionals.

There have been other times when consumers have had to seek privacy and time for sexual expression outside of the residential environment because their attempts at it were continuously scuttled by staff intervention. Unfortunately, some of the consumers felt it necessary to take their lovemaking into the public arena. There have been reports that consumers have been caught in restrooms at local convenience stores, discovered in public parks, found expressing affection into darken hallways at shopping malls, and even taken to alleyways while on breaks from their work. If given the choice, and if money were not a factor, most consumers would gladly check into a motel for a day or evening of intimacy. However, due to structural concerns (e.g. accountability, lack of funds, the need for supervision, transportation, and so forth) this is not a very likely response to
Table 4. Results of SMRAI by Group Score (N=63).

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such situations. One consumer interviewed for this study commented on the frustration he felt when living within a group home environment. He stated that it was tough having a girlfriend in a group home:

...because you only go to see your girlfriend two times a week and on weekends. I broke the rules a lot on that. I felt that that rule sucked. You could only see your girlfriend two times a week because everybody would be spending time with their girlfriends and nobody would be spending time at the group home....you got your chores (Respondent C-8, 1993).

We had to pick our own spots [for privacy]. Like the parks. (If you wanted to get intimate?) Yea, we had to go to parks. We didn't think about getting caught. There's people going in and out of there all the time. We waited until the park seemed empty. We'd go into the woods and bang it (Respondent C-8, 1993).

This consumer even commented on the sex lives of lower functioning disabled, stating:

When I lived at the [name] group home, I learned that disabled people can't punch it. They just can't do it. Either they're not interested or the houseparents tell them they can't do it. (What about homosexuality?) Oh Yea, yea. I did experience one. That was at [name of home] (Respondent C-8, 1993).

Another consumer discussed her frustrations over having to put up with rules and guidelines in a group home environment:

Um...there was one [rule]. Dating rules. I remember this much. I had a thing for somebody. I just didn't like the rules about dating. No holding hands, no guys in your room. I didn't like it. I wanted to date a guy I lived with and couldn't because he lived in the same place. It took me a long time to get over him. It was really hard (Respondent C-20, 1993).

Another consumer voices some of these same concerns. Talking about sex she stated:
We had to find hiding places like, wow. Well, we had to go like to ghost town [a park with small buildings for kids to play in] or into the woods or there used to be a building not too far from [name of building]. Or we went to other places to have sex (Respondent C-17, 1993).

Finally, one consumer gave insight into how staff don’t even think of their consumers as sexual beings:

This [pregnancy] was a surprise to me.....I was on birth control...I was still taking them. I did not find out until last part of May [year] that I was six months pregnant. (No one even knew?) No. (Weren’t you a little surprised when your periods stopped?) Yea....I didn’t even know. I did not go through sex education. (Respondent C-11, 1993).

Thus, it would appear that as a potential obstacle to normalization, concerns over negative staff attitudes and behaviors towards their consumers is real. The saddest thing about the social arrangements just described is that the consumers who get caught expressing the love they feel for another person in a public setting get a double, or even triple, label assigned to them. First, they are considered "retarded." Second, they are considered deviant in that they attempt to express themselves sexually. Third, their attempts to do so with dignity may be stifled, thus, making them go out into the public in search of a location for their sexual behavior. Finally, if they are caught in the act in public, their deviant label is refined even more. The options are then clear at that point. The consumers can agree to go along with the program as dictated by the residential service agency, or they can opt to continue with their "deviant" ways. If consumers are caught again, more formal sanctions are probably called for which will probably act to restrict the persons' ability to make contact with their friends, or even to travel into the public arena without supervision. And what are consumers to make of all this? What
messages are given to them about human sexuality, their self-worth, and their self-concept?

Individuals with developmental disabilities have much of their sexuality dictated to them by the structure found within their residential setting. There are some residential settings which do not offer the necessary privacy for conducting intimate relations. Privacy is no doubt a crucial commodity for these persons, and, without it, consumers will be hard-pressed to develop that part of their self. In a traditional group home setting, access to privacy may be different for individuals as some may indicate higher functioning cognitive skills. For others it may be a temporal situation based upon various structural elements, and for others it just may be impossible due to the number of residents involved. Since each person receiving services may have different needs, desires, and abilities, the service organization should see to them, no matter what form their present housing situation takes.

Part of the spatial analysis of residential settings provided an opportunity to discover whether or not the physical surroundings offered consumers the freedom and privacy needed to express their sexuality. This part of the study took into account traditional group homes, waiver homes, and large apartment complexes. The apartments' environments were not examined due to the fact that it is widely accepted that those who receive services from that program have, for the most part, no problems with respect to privacy. The assumption I have always held is that as residential environments neared the traditional group home format, the less likely it would be that adequate privacy would be made available. Results of this portion of the spatial analysis were predictable.
Of the seven traditional group homes examined, all reported having rules that restricted contact between the sexes. In particular, the bedroom areas were separated into male and female "wings." When the RPMs were asked if their houses provided a private area or room for the purposes of allowing their consumers their right to engage in sexual expression, none of the RPMs responded that they did. One RPM expressed her thoughts on the subject of consumer sex at home in this fashion:

You know they can't do it [sex]. According to [the] rules, we have to keep them separated and sex isn't permitted, or else we'd lose our license. (Why?) I was told that by my supervisor. (What are your personal thoughts?) It's ok because they wouldn't understand a thing. (Why?) They don't know about it [sex]. (Have you ever found residents masturbating?) Yes. I've 'caught' some and I tell them to stop. It gives me the creeps (Respondent H-6, 1993).

Another RPM reported that no sex was allowed in "her house" when she worked her week. Yet, another RPM explained that the consumers are kept away from sex-inducing situations. She felt good about that and about her house's physical structure which acted to separate men from women. However, she was quick to add that there was little they could do about the homosexual sex that went on in the dormitory wings at night:

My husband and I get really bothered by the sounds we can hear from the wing areas. We hear the whispers and we hear the noises (What noises?) The moaning. God! Its such a turn off to hear them engaged in stuff. We know it goes on, but what can you do? My husband has got up from bed and told them to "quiet down" so we can get to sleep. They may quiet down, but they don't stop all together. (How is it that you can hear them?) We have the intercom system set up through out the house and our speaker is in our bedroom so we can hear if one of our clients needs help at night. But we can hear it all (Respondent H-5, 1993).

Another RPM demonstrated what can only be described as ignorance about those with whom she works, thinking only in terms of her own convenience:
Those "down types" [down syndrome] don't have a clue. They just aren't smart enough to understand what they are doing. We see them pretending to know, like when they mimic what they see on t.v. We kind of informally discourage that stuff. It's like an informal house rule we all follow. (Do you have a room for someone to use if they want to?) No room for sex. No way! We don't want all the problems that go with that. (Like?) Like pregnancies, birth control, fights, and jealousy. (Respondent H-3, 1993).

Many RPMs who worked at traditional group homes, and at some waiver homes, appeared to be uncomfortable discussing the sexuality of their consumers. In some ways, they presented their consumers as asexual, void of sexual feelings and desires. Given the fact that certain realities must be faced if sex was made a part of their consumer's lives, perhaps an attitude of "what they don't know won't hurt them" was one way to deal with the issue. One RPM perhaps summed it up best when she commented that if her consumers all became sexually active, it would make her extremely uncomfortable. I believe that the staff who work in traditional group homes have little to fear because the house structure is set up in ways that will preclude sex from ever becoming a problem for them.

Of the four waiver homes analyzed, the structure of the residences and RPMs all presented a different approach to dealing with the issue. At one home, there were rules that separated the sexes. When asked for a copy of the "house rules" which officially informed the consumers about this, the RPM showed me a list, but nothing was mentioned about separation of the sexes. When asked about why it didn't appear on the list of rules, the RPM said that it was just "understood" by all concerned. In the other waiver homes, none of the RPMs could produce a list of house rules or guidelines. Another RPM in a waiver home suggested that they went by the responsibility level of
the consumer as to whether or not he or she was allowed to engage in sex. Thus, if the consumer was evaluated by the house staff to be responsible, sex was then allowed.

When asked about the criteria for judging their consumers, one RPM explained:

We have this one client who uses his bedroom for sex with his girlfriend, but we finally had to tell him that if he couldn't have "quiet sex" that we would stop them from having sex. (What do you mean?) I mean that he was loud. Everyone could hear him groaning, moaning, and....you get the picture. It was gross for everyone. I even opened the door on them once and told them to knock it off with the noise. He's gotten better at it now. They learned they had to respect those around them if they were going to keep going (Respondent H-7, 1993).

At another wavier home, the RPM said that sexual contact was limited through an "informal" type of discouragement. Another RPM indicated that there were no rules against it and that accommodations would be made if the consumers demonstrated an interest in taking part in an active sex life, but none had to date. She explained that many of the consumers she had worked with over the years had been conditioned to think of sex in a negative way. Acceptable ways to show affection would be holding hands and perhaps a kiss, but sex was something that was not to be engaged in outside of marriage.

At the apartment complexes, the sex life of consumers was not considered a problem beyond the fact that a few of the women had become pregnant. Some opted to keep their babies while others opted to abort. However, all of the staff indicated that their consumers were free to practice sex as they wished, as long as it was done so in the privacy of their bedrooms. Even group sex reportedly had taken place without staff intervention, perhaps without staff knowledge at the time. The central rule that seemed to govern sexual expression at the apartment complexes was simply that as long as it was
done in privacy and no one was getting hurt, then it was accepted. It would appear that having one's own apartment seems to be the key to an active, dignified sex life. When asked about the troubles faced with such an "open" policy with respect to sex, one RPM stated:

We've had lots of sex at the [name of residence]. When we first opened, it was a question my supervisor discussed with me. It was decided that [if] sex was going to be allowed, then it would be in their bedrooms. In addition, sex education classes would be held and birth control would be monitored closely. We've only had a few problems, but nothing major. (Respondent S-02, 1993).

A couple of women had abortions, and one set of houseparents really had problems with this. It was messy. I presented my girls with both sides of abortion. Then, on the other houseparents' week, they showed them anti-abortion films and said to one woman that they would care for her and her baby if she decided to keep it (Respondent S-02, 1993).

Can you believe such one-sided pressure! I was really mad at them. Thankfully, the women had enough will to know and follow their own minds. But, in general, sex has not been a problem for us (Respondent S-02, 1993).

Given these data, it must be concluded that the potential for covert and overt excessive control of consumer sexuality is present. Attitudes voiced by the RPMs during interviews and other staff by way of the SMRAI, certainly suggest that some staff have some very strong feelings against this type of behavior. If staff cannot regard their consumers are sexual beings, and if they are unwilling to accept and provide for such behavior, then what conclusion should members of the wider society draw from all of this? It may be that stereotypic images of over-sexed, mentally retarded persons standing around while masturbating in public will always obscure the true nature and humanness of individuals with developmental disabilities.
Somewhat related to the issues already discussed is the area of excessive social control and physical, emotional, and sexual abuse. These are the next topics to be discussed and analyzed. Clearly, if these things are found, they most assuredly would impact upon the agency's ability to meet its mission statement goals of normalizing their consumers.

Abuse of Consumers

The data surrounding abuse and surplus social control provided insight into staff activities that present a picture that is filled with potential obstacles to the normalization process. There is compelling evidence to support the notion that consumers are faced with situations in which excessive social control - control that goes beyond the scope of any approved IPP - is exercised. One possible root cause for this was captured by a RPM who freely discussed his ideas about how excessive amounts of social control impact negatively upon his and other consumers:

I mean, we all control those people in many ways. We can't get around it. It's part of the system. I mean we control them by developing IPPs that dictate behavior they are suppose to follow. If they don't, they are faced with the consequences of one sort or another (Respondent S-90, 1993).

There are many ways [to manipulate consumers], like communicating with their doctors and telling them of behaviors and other problems before they see the person. We have helped some of our residents' doctors in setting doses for some of our residents by informing them of certain kinds of behavior that would bring about increases in the kinds of medications they receive, especially tranquilizers that help us deal with radical, emotional behaviors (Respondent S-90, 1993).

We withhold information from them. Mail, like sales adds and things, never get to them. We hold meetings to discuss how we are going to control situations, like who a resident should or should not see. We implement house rules to modify behavior, and the list can go on. But you get the point. It's done all
the time and everyone in the company knows about it. They just won't admit that it goes on. There are times when ignorance is bliss, but if the whistle ever gets blown.....wow (Respondent S-90, 1993).

Somewhat related to the topic of social control is that of abuse. Abuse is a "hot button" in the human service field. Charges of abuse are to be taken seriously, and whenever individuals with developmental disabilities are involved, increases in vigilance is called for due to the fact that often such persons feel intimidated and powerless to inform anyone about such unhealthy climates. My study asked a series of questions that, because of the sensitive nature of the subject, merely requested a "yes" or "no" response. The results from this portion of the questionnaire are tabulated under Table 5 below.

The results indicate that 50% of staff have either personally taken part in the physical abuse of their consumers, or know of staff who have done so. With respect to emotional abuse, 77% of the respondents indicated that they, or other staff members they know, have taken part in the emotional abuse of consumers. Lastly, 27% of respondents reported taking part in, or knowing staff who had, sexually abused consumers under their care. The important thing to note about the questions over these different kinds of abuse is that these questions were couched in terms of cases in which staff had "gotten away with" the abuse, and not cases in which perpetrators were caught and turned over to agency officials.

While it is clear that such questions are subjective, it is also clear that most staff members working in residential services have a very good idea of what constitutes abuse and what does not, and, according to agency officials, staff receive annual training on the subject of reporting abuse. Given these facts, it is depressingly clear that even if one-
third of these data were not true, the result would still be to conclude that an unacceptable level of abuse and surplus social control takes place. Most of the statements listed in Table 5 have the potential for impacting upon the tenets of normalization and the basic rights which, again, appear to be a significant part of the target agency's service philosophy and stand in stark contrast to some of the rights consumers are granted by the agency. For example, the right and need to be free from abuse is clear. Studies have shown the effects of repeated abuse over time, even abuse that occurs between intimates, e.g., low self-esteem, feelings of inadequacy, powerlessness, and so forth (Gelles and Cornell, 1990).

To further examine the topic of abuse, I asked respondents to recall both the number of times during the past twelve months they remembered situations involving physical, emotional, or sexual abuse. Of the 62 respondents, 43 (69%) indicated that they recalled situations involving abuse. Even when two extreme responses (352 situations) were treated as outlayers and discounted, the mean number of incidents reported was 5.02 per reporter.

**Surplus Social Control**

When analyzing the data pertaining to reports of situations when surplus social control was employed, responses presented a mean of 9.3 events per reporter. While abuse is somewhat easier to understand, I wanted to make sure I grasped the subjective meaning respondents were attaching to. Of these responses, I invited respondents to list the means by which they excessively controlled their consumers. Specifically, I asked respondents to provide a few examples of the types of staff behavior that they, or other
staff, engaged in. However, prior to turning to those data, I believe that the remaining
data contained in Table 5 above needs to be revisited and discussed under the topic of
social control.

Beyond asking about specific types of abuse, I also wanted respondents to indicate if
they had taken part in, or knew of others who had, behaviors that were related to surplus
social control. According to the data in Table 5, 86% of respondents indicated that
consumers' personal choices were denied. This can be accomplished through a wide
variety of means, including withholding critical information concerning options,
restricting the number of specific choices, or blatantly refusing to entertain a consumer's
desire or demand. Likewise, another way is to tamper with the mail, in some cases, a
very serious federal offense. Even though such an activity is highly irregular, 73% of
the staff responded that they, or others they knew, had opened mail addressed to
consumers without the consumer's knowledge, and, thus, without their permission. I can
only imagine the staff's reaction if their supervisors stood outside of the staff members'
homes and opened their mail, deciding what was given to them and what might be
withheld.

It appears rather strange that for a company whose core principles acknowledge the
need for real options for its consumers, suffers from such hypocrisy. Rather than
ensuring that each consumer's rights are maintained, several employees report rather
significant numbers of "infractions" with respect to excessive social control and social
or environmental manipulation. Sadly, I must admit that having worked for other
agencies, what is expressed by the these employees is the norm, not the exception.
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<th>Staff Responses Concerning Abuse and Surplus Social Control (N=62).</th>
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<tr>
<td><strong>1.</strong></td>
<td>Staff physically abused consumers.</td>
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<td>YES 50% NO 50%</td>
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<td><strong>2.</strong></td>
<td>Staff emotionally abused consumers.</td>
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<td>77% 23%</td>
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<td><strong>3.</strong></td>
<td>Staff sexually abused consumers.</td>
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<td>27% 73%</td>
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<td><strong>4.</strong></td>
<td>Staff knew of situations in which consumers are routinely manipulated by staff.</td>
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<td>87% 13%</td>
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<td><strong>5.</strong></td>
<td>Consumers abused other consumers while under staff care.</td>
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<td>53% 47%</td>
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<td><strong>6.</strong></td>
<td>Family members abused consumers.</td>
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<td>55% 45%</td>
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<td><strong>7.</strong></td>
<td>Consumers' personal choices were denied.</td>
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<td>86% 14%</td>
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<td><strong>8.</strong></td>
<td>Staff opened mail addressed to consumers without the consumer's knowledge.</td>
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<td>73% 27%</td>
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<td><strong>9.</strong></td>
<td>Staff yelled at consumers</td>
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<td>81% 19%</td>
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<td><strong>10.</strong></td>
<td>Staff purposely punished consumers in some fashion that went beyond any IPP guideline.</td>
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<td>57% 43%</td>
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<td><strong>11.</strong></td>
<td>Staff bullied consumers.</td>
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<td></td>
<td>73% 27%</td>
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<td><strong>12.</strong></td>
<td>Consumers were set up for failure by staff.</td>
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<td></td>
<td>71% 29%</td>
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<td><strong>13.</strong></td>
<td>Staff could not stand it when they thought consumers &quot;got away with things.&quot;</td>
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<td></td>
<td>87% 13%</td>
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</table>
A majority of respondents also reported yelling at consumers (81%), punishing consumers unjustly (57%), bullying consumers (73%), and setting consumers up for failure (71%). When speculating about why such situations take place, I believe that many of the problems stem from staff members devaluing their consumers because of their limited cognitive and physical abilities. In effect, they justify their behaviors because they view them a something less than fully human. Another way of looking at it is that staff egos become involved in staff/consumer relationships. In discussions with other staff, I have heard them express how they cannot stand for their consumers to "pull one over on them." Respondents clearly demonstrated that ego involvement did make up part of the picture, as 87% indicated that staff members have a difficult time when they believe staff "got away with things."

In addition to responding to the questions contained in Table 5, I requested that respondents provide examples of how they, or others they knew, excessively manipulated and socially controlled their consumers. A list of the ways in which staff practice methods of surplus social control is continued in Table 6, below. Some of these methods are probably not intentionally used as a means of excessive manipulation, but result from structural forces in which staff work and consumers must live. For example, when a staff person is responsible for making sure that 11 consumers are prepared and on time for a group outing, and then one or two of the consumers decide not to go, a staff member may feel justified in attempting to coerce the consumers into taking part with the group. In addition, when consumers have a bad day at work they may decide to strike out at others after arriving home.
From this sample list, it is easy to see that exploitation of situations takes place within residential settings. The important question is: How can this take place? Some may speculate that it has to do with an agency that knows these practices go on, but tolerate it because to do otherwise would be utterly self-defeating. Others may think that what they are doing is justified by any number of reasons. For example, considering the amount of paperwork required each day, staff members may feel justified in resorting to a "whatever-works-is-ok" response. However, what also happens is that staff get involved in ego-trips and power plays and often end up battling with their consumers, adopting a "never-say-die" position. Such situations often escalate very quickly since consumers may not understand their own emotional responses or the situational variables at play. At other times, frustrations arise out of pure boredom and routine. One consumer who lived in a group home captures this type of frustration, as well as the manipulative techniques used by the staff, when he described a part of his life in his home:

We got'ta all go together to the same place all the time. I like the dances, cause I see my girlfriend and we like to dance. I don't like going to sport things and ball games. They make us sit like a group and people stare at us a lot. I get mad, but my house-parent said that I have to go or nobody gets to go. I don't want my buddies to be mad at me, so I go too. I like to go walking, but I can't go very far alone. They got'ta go with me all the time. I can walk to the store alone, but that's the only place (Respondent C-25, 1993).

Another consumer recalled what life was like while living in a group home environment. Again, the manipulation is apparent, as is the internalization of the interaction between the staff member and the consumer.
Table 6. Examples of Ways in Which Staff Practice Surplus Social Control.

1) not giving choices; only those choices staff prefer on social outings;
2) phrasing requests, statements, questions in certain ways to elicit desired response;
3) withholding privileges until desired behavior is arrived at;
4) house parents don't interact with clients - then clients don't know options;
5) staff make clients go to bed before dark and stay in bedroom until 8:00 a.m. on weekends;
6) staff threaten clients by telling them they will call the supervisor, doctor, or client's parents;
7) "suggest" things to clients - "Boy, you sure look tired...why not go to bed?";
8) give clients guilt trips if they get out of line or don't go along with programs;
9) use of psychology, blackmail, bribes to get desired behavior;
10) offering clients only negative options - they'll back down;
11) staff rephrase question until clients give "yes" response;
12) removal of pool table balls for no reason whatsoever;
13) withholding letter from girlfriend of client which drives client crazy - informal agreement to have mother decide what to do with it;
14) offering choices that staff know the clients will refuse and then offering them one they know they will accept;
15) intimidation through suggesting punishment of what will happen to clients;
16) clients really don't understand their IPPs;
17) tone of voice, language, and use of rewards;
18) punishment;
19) publicly humiliating clients;
20) staff making false promises to clients;
21) use of "parental" body language and voice;
22) yelling at clients;
23) planning meals without asking for input from clients;
24) repeatedly ignoring requests for attention made by clients;
25) making choices for clients;
26) giving out personal allowance (weekly money) only if clients go bowling;
27) breaking trust built up between staff member and client by suggestions;
28) just telling them "no" in a stern voice;
29) threatening to move them to lower functioning house when they act up; and
30) slamming the door in their face - that gets their attention.
Yea, they [staff] told us what to do all the time in the group home. When we got home I wanted to relax and watch t.v., but they told me to do my chores sometimes. If I argued, I got yelled at; so I just did it. I just tried to stay out of the way until supper time when we all ate together at big tables in the dinning room. They told us to do this or that all the time. I stayed in my room sometimes, but they yelled at me for that too. I didn’t know what they wanted sometimes (Respondent C-29, 1993).

Another consumer also points to the pressures staff can apply:

I get mad sometimes when I want to go over to a friend’s house or out to the bar for a drink and my counselor gets real uptight about it. She thinks my friends are bad for me, but they’re my friends. I invite them over sometimes, but I know my house-parent don’t like it. We laugh at her [the advisor] and my friends tell me to do things anyway. Sometimes I get real mad when I want to buy a CD and my houseparent tells me I can’t. She keeps all my money and writes our checks out for us. I don’t like how the [agency’s name] won’t let me go home when I want. I like to see my mom and family. I miss them. I hate that (Respondent C-26, 1993).

Likewise, when an independent-living consumer was asked about control:

I feel that I am not controlled, but I still need help with some things. When I ask my counselor for help, sometimes he just tells me what to do instead of listening to me. I get mad and he asks me why I asked him in the first place. But he’s ok most of the time. I talk to him about a new day program, but he doesn’t have any idea what I can do because I have problems with things. I hate cutting out squares of cloth all day long. I get bored and angry and then my boss gets mad at me. I was told to stay home for five days two weeks ago when I got in trouble (Respondent C-27, 1993).

However, I believe the more serious social control and manipulation occurs within the ranks of the higher functioning, more independent-living group of consumers. Within this group is a collection of unwed mothers who have been assigned drop-in advisors. These advisors provide different types of services, including training in parenting skills, independent living skills and assist in many other areas. Because many of these
consumers have only limited contact with others, advisors often act as confidants and friends. These are situations in which the disequilibrium of power becomes apparent. On one hand, these consumers have gained a great deal of independence, often due to effort on their part. Advisors, on the other hand, still control many facets of their lives. For example, most, if not all, financial dealings must be cleared through them, as well as assisting in transportation needs, medical needs, and administrative charting. There are times when the multi-dimensional role of the advisor may make them feel justified in becoming involved in what others may consider very private, personal realms of their consumers, which, in turn, can lead to gross manipulation.

One young mother voiced a concern when it came to her advisor becoming too intimately involved in her personal life, and how psychological and emotional manipulation were used as methods for conformity. She expressed her frustrations over having strangers come in and evaluate her skills as a mother:

Well, they got this new respite thing...they're going to have someone stay with us overnight to see if the baby is getting up at night. And to help me get him potty trained. Someone is doing it from 3:00 to 5:30 and then at 6:00 to 10:00 and then someone stays all night (Respondent C-19, 1993). (How do you feel about that?)

There was one time when I felt so mad I wanted to give him [the baby] up for adoption! Take him and leave me the hell alone! All this crap (Respondent C-19, 1993). (Tell me about it. What's going on?)

This respite things....they're going to be around here around the clock. They're going to change things all around....our schedule. We have to break the baby's routine for sleep, food, and bathing. (Respondent C-19, 1993). (What brought all this on?)
They don’t think I am a very good mother. They don’t think I use enough discipline or do a whole bunch of things right with him. They think they can do better with him. Maybe some of it is true (Respondent C-19, 1993). (Do you feel they are working to take the baby away?)

I think they are trying to come up with something real stupid so they can take him away. I think they just want the baby. My mom has told me that all along. I told them [the agency staff] that and they said, "Oh, no we’re not." BUT THEN THEY TELL ME IF I DON’T DO THIS OR THAT, THEN THEY’LL TAKE THE BABY AWAY (Respondent C-19, 1993).

I asked my advisor why I always get told that and she said, "Because it always works." My advisor told me that they [the advisors] use that with everyone [all mothers getting services]. They threaten everybody with their kid. The advisors threaten everyone by threatening to take their babies away (Respondent C-19, 1993).

While the above example is alarming, most of the consumers interviewed for this study indicated that they did not feel that rules controlled them to a point of discomfort. Often I received responses like, "Things are ok," or, "The rules don’t bother me," or, "The rules aren’t too bad here." When they did mention concern, it often had to do with their previous living arrangements, especially if they had lived in a traditional group home. Very few of the consumers who resided in their own apartment expressed concern over rules. However, it must be noted that the agency still maintains significant amounts of control over these persons. Many have their finances controlled by their drop-in advisor, transportation is still a problem, many complain of social isolation, making their advisor someone whom they would not want to alienate because of their emotional dependency.
The last area in which potential obstacles may exist is that of physical environments found in residential settings. The agency offers a wide variety of residential settings, ranging from highly structured group homes to less structured independent apartment settings.

The Agency's Responsibility: Illusion or Reality?

A person might conclude that the direct-care staff who work with such persons on a daily basis would be the first to defend their consumers. That of all persons in the community, agency employees at all levels would be the most sensitive and caring advocates for their charges. However, as my study suggests, this may not always be the case. In fact, when examining the agency at the direct-care staff and the environments in which they worked, I found several sources for concern, including the presence of abuse. Not acting to remove obstacles whenever possible is tantamount to perpetrating the cruelest of all jokes that could possibly be created and directed at persons with developmental disabilities. Within the residential services, one director summarized the importance of attitude within the work environment. She stated,

If the direct-care providers don't buy the agency philosophy of normalization, the clients we serve don't stand a chance at success (Respondent M-3, 1993).

This applies to situations in which abuse and other forms of ill-treatment take place. It has been my experience that many employees in the agency operated from a "we-they" interactive mindset that breeds negativism. Results from my survey indicate that in many areas employees report attitudes that stand in stark opposition to the agency's written philosophy of dignified treatment and human rights. However, the key question really is:
Do these attitudes lead employees to unacceptable forms of behavior? Based on my data, I cannot answer the question directly. However, I feel that by having used a plethora of data collection techniques in my study, I feel comfortable in offering a somewhat qualified "yes" to the question.

For example, I believe that it is a fair assumption to feel that abuse and surplus social control takes place in every home setting, and on a daily basis. Most employees at all levels not only reported knowing about such activities, but they described how such behaviors were routinely carried out. I have witnessed persons within the agency engage in emotional abusive behaviors, as well as have consumers come to me and report situations in which they were physically abused by staff. I did what the company expected of me - I turned these reports over to my supervisor. When I tried to follow up on my reporting, I was told to not concern myself with the situation, that it was out of my hands and had been passed on to the responsible parties. Subsequent discussions about those situations seemed to imply that the agency does not like to receive this kind of "bad news."

The message I received was simply, "do not turn in such reports because it upsets the agency." If this is the message given out to staff agency-wide, then it may work as a "green light" for taking part in unacceptable behavior. Given the results from my survey in the areas of abuse, I would conclude that this may, in fact, be one of the reasons why so many cases were reported. One example of how such a pervasive attitude impacts direct-care workers was captured by one management-level employee who commented:
We have this attitude, this thing about abusive language. But we have staff who feel that when consumers use abusive language toward them [the staff] that it is ok to say that language back to consumers. I have heard staff call consumers names to their faces like, dummy, stupid, asshole, stubborn shit, and saying things like you're pissing me off (Respondent M-11, 1993).

The difference is teaching them that when you do some of these things and you're not with us, this is what could happen. I think they have the right in their own homes to be treated with respect. I tell my staff to not nag them to death, but it doesn't do any good (Respondent M-11, 1993).

With respect to "bad news," one direct-care staff member stated that, "...they don't like to react to such things." With respect to this "no news is good news" attitude, a certain fear develops which directs staff to not discuss such incidents; that to do so will probably result in the loss of one's job. However, again, it depends upon whose doing the talking. Some management-level and many direct-care staff feel this "do as I say and not as I do" problem is directly attributable to the agency's leadership. One management-level person who talked about this responded:

I have seen [name of agency] sweep things under the carpet and forget about things. Let me just say that it was officially recorded as not being abuse, but rather "horseplay" during which time a client was injured. Everyone knew better, including staff (Respondent M-8, 1993).

Another incident occurred when the agency found out that one so-called important person in the community was turned in by a client for sexually abusing her at work. The way I heard it was that the agency didn't do all that it could have done to protect the client and her family. They allowed her to go back into the situation with just a promise from the jerk to not sexually abuse her again. Can you believe it (Respondent M-8, 1993)?

I think the word out was to keep this incident quiet, but that's a joke at this agency. If you want to hear about something, just go to [a list of local bars] and you will hear very confidential information being blurted
out by one of the biggest upper-ups in the agency (Respondent M-8, 1993).

When another management-level person was asked about the procedures she would follow in reporting abuse, she commented that the agency didn’t really want to hear about abuse:

[name of agency] has this reputation to uphold as the leader in residential rehabilitation. The agency has this thought that they are tops in the nation in what we do. I’ve got to tell them someday that as far as some are concerned, the agency is at the bottom (Respondent M-1, 1993).

With respect to abuse, the agency is now dealing with some abusive situations that have happened outside "our walls" with a couple of clients. They were involved with people who were not our clients. The panic in the agency is running high right now because we can’t do damage control. That’s the biggest thing, not the welfare of the clients (Respondent M-1, 1993).

Another situation points out how staff seem to know how to not handle such situations. There was a client found in a bathroom stall with a person who was not a disabled client. When asked what they were doing, the client said they were masturbating. That was all that was asked of him. Staff didn’t ask if there was a need for an HIV test. Staff didn’t ask the most appropriate questions. They didn’t follow up properly. They didn’t submit an incident report. Everyone in management knows about this (Respondent M-1, 1993).

The situation is being followed up now, but not at the supervisory level. It is being followed up by one of the program directors....for damage control sake. Forget the clients.....it’s the agency’s image that might be hurt if the incident is not followed just so (Respondent M-1, 1993).

One direct-care worker summarized his feelings on reporting abuse like this:

The agency does not want you reporting abuse for the clients' sake, but only to cover their asses. If there is something really obvious going on, then they need you to report it so they have the necessary paperwork on file, but other than that, they don’t want to hear about it. It’s kinda like that with a lot of things with this company. Those making decisions don’t really know what its all about down here (Respondent H-3, 1993).
When so-called "normal" people strike out and abuse consumers, the result of can be devastating for the victims. Often it is not clear if the consumers understand such behavior. In addition, the power structure is such that many consumers most likely will not report the abuse. The amounts and types of abuse perpetrated on consumers can be understood from different perspectives. First, direct-care staff work in a very stressful arena, with demands that can be difficult to meet. Most direct-care staff fill a variety of statuses and play any number of roles, often at the same time. Depending upon the exact environment, staff can be responsible for five to seventeen consumers. Each with his or her own personalities, expectations, and needs.

Further, direct-care staff often view themselves as "put upon" by the agency and those who supervise them. They are often the lowest paid employees who "slug it out daily in the trenches." Turnover and burnout among staff is high among residential workers. They often view themselves as victimized by the agency as they just "try to do their jobs the best they can." As the frustration factor becomes critical, some staff can snap. The results are often short-fused tempers, and, at such times, confrontations between staff and consumers become near impossible to derail. One management person felt that the high degree of frustration and anger that often builds up in direct-care staff is due to the unrealistic demands and hypocritical nature of the agency:

The agency expects their employees to be loyal to [the agency's name] and consequently loyal to management. Most often this promotes unspoken dissatisfaction due to the fear of speaking out or expressing an opinion (Respondent M-7, 1993).
Another management-level employee discussed the issue of abuse directed toward consumers in this manner:

Their [the staff] day at the group home is often dictated by the type of day they have had at their own home. A lot of baggage is brought to work with them. We have a lot of people addressing clients in a less-than-appropriate manner. That's one of the hardest disciplinary matters we have to deal with (Respondent M-11, 1993).

If they come to work in a bad mood and you try to address the fact that they need to be presenting options in a positive manner, they tend to get a little upset and then things get worse for the clients. I'm beginning to think that we have some really burnt out folks who don't realize just how burnt out they are. I think as an agency we're gonna have to start dealing with mental health issues for staff (Respondent M-11, 1993).

One of the reasons the agency may not want to deal with abuse and excessive social control is the fact that whenever charges are made, and the state's Department of Inspection and Appeals steps in, the issue becomes public. The local newspapers report such occurrences and those involved, both guilty and innocent, may be suspended temporarily from work, but their reputations may be tarnished forever. Such things must be placed in the balance when dealing with protecting consumers from reports of abuse. However, it is clear that consumers' rights and consumer protection must come first.

Therefore, instead of passing information on and making allegations formal, the agency may feel compelled to handle things "in house." They can also act as "damage control experts" who treat the situation, but maintain the agency's image to the outside world. The only problem with this is that while the intention may be good, the perpetrators, or even those suspected of taking part in abuse, may be terminated by the agency. In essence, the agency has taken care of their problem by getting ride of the party, but they
also, by way of their silence, make it possible for those same persons to be hired by another agency.

**Physical Environments as Obstacles to Normalization**

In order to examine the extent to which the target agency's residences were normalizing in character, I employed a modified version of the Characteristics of Physical Environment (CPE), developed and used by Jacobson (1990). Of particular interest was the scale in the CPE entitled, "Normalization of Physical Environment." This scale consists of eleven indicators of normalization, ranging from rating the inside appearance of the home to evaluating the amount of privacy a resident can expect to have. The importance of the physical environment cannot be underestimated with regard to normalization. That is, the physical layout of the residence can have significant impact, negative and positive, upon the liberties or restrictions facing the consumers who live there.

For example, if a residence has limited living space, yet must accommodate several consumers on a 24-hour basis, the consumers will most likely encounter space usage limitations and restrictions regarding access into certain areas. Privacy may be an issue, house rules may be put in place, and given the staff-consumer ratio, outside travel may be restricted to group ventures. Additionally, activities that we take for granted when it comes to individuality, may not be so for consumers living within such an environment. For example, bathing and showering may have to be done at certain times, meals may have to be prepared and eaten as a group, as well as clean-up and bedtime occurring at assigned intervals. Obviously, such routines do not fit neatly into a program in which
consumers are to be normalized in a home-like setting.

The agency maintains eleven group homes, nine waiver homes, a few apartment complexes, while a large number of consumers live in their own apartments throughout the community. Since this latter group would most certainly fit well into the expectations of a normal residential environment, I did not concentrate my analysis on those locations. However, during interview visits, notes were taken on neighborhoods, locations, and inside appearance. The spatial analysis primarily was employed to analyze the other residential settings. Of the eleven group homes, seven were selected and spatial examinations completed. Of the nine waiver homes, four homes were selected for analysis. Finally, two apartment complex units were analyzed. Results from these spatial analyses are included in Table 7, below.

Waiver homes were normal in outward appearance, fitting fit nicely into their respective neighborhoods. Likewise, the staff-consumer ratios were somewhat normalizing with all homes having five consumers to one staff i.e., they all presented a family-like atmosphere. In contrast, while traditional group homes appeared to fit into neighborhood settings, they were large, one floor homes that presented a somewhat uncommon appearance. In addition, the staff-consumer ratio was more of a concern for the traditional group home environments. With the exception of one of these group homes, all had a ratio of 11 consumers to 1 to 2 staff persons, depending upon the time of day. Finally, the apartment complexes were located in and around neighborhoods where other apartment buildings were located. One of the complexes had up to 17 consumers with 1 to 2 staff present, again, depending upon the time of day. These
apartment complexes fit well into the neighborhood. The CPE scoring scheme requires
the observer to examine.

It probably comes as no surprise that traditional group homes received the most
unfavorable ratings. For the 11 items, traditional group homes received "no" marks on
six of the eleven factors. Group homes were typically dark on the interior, many
furnished with dark brown furniture and dark carpet that was often poorly maintained.
Some of these homes had what I refer to as inside/outside carpet that had no or little
padding. In addition, wall furnishings were neither too attractive, nor arranged
appropriately, e.g., some arrangements were missing parts, turned or rotated out of
place, or very out-of-date in style. While bedrooms in group homes appeared to be
individually decorated, staff often mentioned that they would impose limitations in some
cases, especially when sex-oriented material such as posters were discussed. For
example, one RPM commented:

We permit our clients to decorate their bedrooms as they want. There really
aren't things they can't do. (What about some really sex-oriented posters?)
There would be a problem there because we don't want to give people ideas.
I would probably strongly suggest they put something else up instead. But
our people can do pretty much anything they want with their rooms
(Respondent H-3, 1993).

When it came to age-appropriate environments, I found that open bathrooms and the
recreation equipment to not be age-appropriate for many adult consumers. Beyond latch-
hook projects, I didn't see much evidence of other hobbies or other activities. Games
such as Monopoly and Risk were stored on shelves, but staff reported that they were not
Table 7. Results of Spatial Analysis

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>Group Home</th>
<th>Wavier Home</th>
<th>Apartment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Inside homelike appearance</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>2. Cheerful, warm interior</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>3. Individually decorated bedrooms</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>4. Homelike appliances/fixtures</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>5. Comfortable, non-standardized furniture</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>6. Age-appropriate environment</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>7. Normal, risk-taking fixtures</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>8. Outside appearance is homelike and lawn maintained</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>9. Private storage for personal items</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>10. Flexibility of interior design</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>11. Design conducive to privacy</td>
<td>NO</td>
<td>YES</td>
<td>YES</td>
</tr>
</tbody>
</table>

used very often. Pool tables were present, but often they were in poor condition and in a couple of homes there were not pool sticks and pool balls were often missing. Interior flexibility was really not an issue since furnishing were purchased by the agency. Staff indicated that the agency does not have the funding available for updating these homes.
In any case, the point is really moot since, according to staff, consumers are not asked for input about changing their homes’ layout.

When it came to privacy, group homes were not conducive to individual needs, especially if you wanted to have private moments with a friend of the opposite sex. For example, since all the group homes had sensitive intercom systems that allow staff to hear into each private bedroom and bathroom, there is no privacy. There were no rooms set aside for couples to use when on a date. According to most staff, "dates" take place in the home, in common areas where the consumers' behaviors can be monitored.

I discovered that specific environments played a big role with respect the need for house rules. It is to these rules that I now turn. I asked RPMs to indicate whether or not they had house rules that governed activities in different areas. Below, Table 8 shows the types of rules and the number of homes that did or did not have them. When asked for a copy of the house rules, only one housing staff was able to produce a copy of the rules for me. This made me wonder if, in fact, the rules were "formal" or "informal." One management-level employee made me aware that recently the staff at one group home were officially sanctioned for having a set of "informal" house rules they imposed upon their consumers. Thus, it came as no surprise to find RPMs somewhat less than forthcoming when I asked for a copy of the rules for their homes.

Rules impact upon the lives of consumers who happen to live in a traditional group home environment, and, to some degree, in waiver homes. The apartment complexes, with the exception of assigning consumers laundry days, were void of any formal house rules. Most of the rules that appear in Table 8 appear to be associated with structural
factors such as staff-consumer ratios and house routines. For example, bedtime hour, commonly referred to as "wing time," is most likely dictated by when staff are no longer "on the clock." Telephone usage is predicated upon the fact that often there was only one telephone line going into the house for staff and consumers alike. In addition, when the telephone is one of the consumers most important means of staying connected with life outside of the residence, they may tend to want to stay on it for longer periods of time. Given the number of consumers who may wish to use the telephone, it is easy to see why some control may be required. Likewise, laundry days must be assigned to avoid over-usage and to preclude clashes between consumers who may wish to do their laundries on the same day or late at night. Once again, the physical environment inside of the group homes, coupled with the staff-consumer ratios make some house rules a necessity. However, given the demands placed on staff with respect to administrative requirements and other tasks, I would be hard-pressed not to believe that some rules are created more for the convenience of staff than for assisting the consumers.

Contact between sexes was another feature of group home living that was limited by the physical environment. Since there are dormitory wings for males and females, there is an unspoken emphasis on keeping the sexes apart, and this was true as well for sexual contact. When I worked as staff in group homes, consumers would run up to "tell on others" for such things as kissing and hugging one another. There was a common belief that once staff began permitting this couple or that couple to hug and kiss, it would not be long before all consumers would begin experimenting. When dates were allowed,
Table 8. House Rules for Group Homes, Waiver Homes, and Apartment Complexes.

<table>
<thead>
<tr>
<th>Type of Rule</th>
<th>Apartment Complex</th>
<th>Waiver Home</th>
<th>Group Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>1. Bedtime Hour</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. Telephone Usage</td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Laundry Time</td>
<td></td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>4. Contact Between Sexes</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. Meal Hours</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>6. Television Watching</td>
<td></td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>7. Recreation Hours</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8. Time Out</td>
<td></td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>9. Visits</td>
<td></td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>10. Eating and Drinking</td>
<td></td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>11. Smoking</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

they were chaperoned when the two persons were within the residence. A goodnight kiss at the door was viewed a permissible. Finally, eating and drinking in group homes were restricted to the dinning room area, and, on special occasions, to the recreation room, e.g., birthday parties, Friday night pizza-movie parties, and so forth. Smoking was also restricted to the dinning room area, the recreation room, or, in one case, to outside the residence.
With only a few exceptions, the rules acknowledged in Table 8 do not look exceedingly difficult to accept. However, according to RPMs, rules bombard consumers as they are subjected to them everywhere they go. Rules confront them at home, at work, and in the community. That really does not sound all that odd since most members of the normal population are confronted with the same. However, what is somewhat alarming is that many rules are of the unspoken kind; the kind of "informal" rules that do not appear in print, but, none-the-less, are understood to exist:

A lot of the rules that govern the lives of my clients are informal. (What do you mean, informal?) Well, take for example the fact that when the agency found out most houseparents were using "wing-time" to make clients go back to their bedrooms at certain hours, they were told that such rules were illegal and not to be enforced in any home. Well, the houseparents got around this by not informing their clients. By this time, they were so use to being told to go to bed at 8:00 p.m. that they did so without being told. You see? By keeping the information from their clients, wing-time is something that "informally" goes on today (Respondent H-11, 1993).

(What other informal rules are there?) There's a lot of them. For example, there aren't really suppose to be any curfew hours. But what houseparent is going to stay up after 10:00 p.m. when they don't get paid? So they let everyone know that they are "off duty" at 10:00 p.m. Everyone then knows that they better be in before curfew time. There's also one about not using the telephone before 5:00. (What is that about?) I mean clients know that they are not to use or get telephone calls before 5:00 p.m., because the staff need to keep the phone open. It also has to do with chores getting done in some homes. Some houseparents want their clients to get some of the chores done before supper. So they can't use the phone before that time (Respondent H-11, 1993).

Snack time is strange. Even eating food and drinking is controlled by informal rules. Houseparents let their people know that they aren't suppose to drink pop or anything outside of lunch, dinner, or if they have a pizza party or something. The reasons for this are different. For one thing the house food budget can't handle a lot of soda buying. Or food, too, for that matter. So eating and drinking must be controlled. There's also the problem with weight gain for some clients, and fights over "copy-cat" behavior. I think clients would drink pop all day long if
they could get away with it. But this stuff is not written down anywhere (Respondent H-11, 1993).

(Why are such things in place....these informal rules?) They’re needed because without them it would be a big mess. Work would pretty much be impossible. If we didn’t have informal rules, people might be a danger to themselves. They might turn into big slobs at home. They might not dress properly, and things like that. In the end, we would hear about it from lots of people, like social workers, DHS employees, advisors. We’d have 10,000 phone calls coming at us. Their rights might take a hit, but we have to do things this way (Respondent H-11, 1993).

A Word About External Obstacles to Normalization

My study also sought to discover whether or not external obstacles, those influences that originate from outside of the agency, might impact upon the agency’s mission of normalizing consumers. External obstacles included such things as pressures originating from funding sources, the activities of other human service agencies, Department of Human Service regulations and guidelines, and advocates, including parents, legal guardians, and planning agencies who have consumers as clients. With the exception of funding, I found that while some of these external factors may influence the agency and its staff, the degree to which they do and their frequency was something that did not impact negatively upon the agency’s general mission goals. One management-level person summarized external obstacles to normalization like this:

The state and county demands that we follow certain rules and regulations. However, there are no rule or regulations existing today that can't be worked with, or creatively gotten around (Respondent M-7, 1993).

Funding is another issue. It can be quite troublesome now and will only get worse as time passes. All human service agencies including our own need to become much more creative in order to get the biggest bang for our buck. It doesn't help [the agency's name] when we go to the county
and ask for more money to spend on inflated programs when others around us are doing more with less. It looks bad (Respondent M-7, 1993).

The only other external problem I see is that of society. It is a problem now and seems to get worse as the economy keeps going down hill. There is less of a feeling to give and help out agencies like the United Way. All of the agencies in the area hurt when the United Way hurts. I think all agencies need to streamline their operations, or at least make a good faith effort to do so. There's a lot of waste out there and accountability will be important to the public in the future (Respondent M-7, 1993).

Other agencies are getting into the act of offering residential services. It will take them time to develop their programs, but make no mistake about it, they are our competition and we have to acknowledge them as such. I think some competition will be beneficial if used to force improvements. So often, however, it's like any other business where one tries to destroy the competition by spreading innuendos and forming alliances, or trying to underbid at the cost of the residents (Respondent M-7, 1993).

Thus, at this time, external obstacles, with the exception of funding, were not viewed as threats. However, funding does have an influence in so far as it drives the agency to follow certain housing programs while leaving others behind. Years ago, it was cheap and thought of as a good idea to spend money on group homes. Actually, group homes still remain very sound economical programs. However, the money for new programs is one reason for forcing the agency to rethink its position on continuing its group home program. The current emphasis is on locating residences in which three consumers might live. Since these are federal monies, and because the county has made it clear that funding has reached its limits, the agency is attracted to it and is heading off in that direction. Pressure from the county certainly plays a role in all of this. One management-level employee summarized the impact of this type of pressure as follows:

Ten-bed homes are still the best thing we have going in the agency. For the life of me, I cannot understand why [name of agency] is so
willing to give up on them. Apartment complexes as well. One of our apartment systems brings in an annual profit of $70,000.00. Why we are so willing to give that kind of program up is beyond me (Respondent M-4, 1993).

The idea of going to a total apartment system is an expensive option, but since the money is federal and not county or state, then everyone is for it. That is no way to run a business, especially since we have clients who would be best served in group homes. For all the talk, I bet money that [name of agency] does not get out of the group home program. I can't believe we would ever do that (Respondent M-4, 1993).

In essence, I believe that pressures from funding sources are making it possible for the agency to experience a period of self-evaluation and change, but I am not totally convinced that it is doing it for any other reason than survival. That is, I feel that the agency is in the process of making decisions that are more business-oriented and showing a tendency to appear less interested in its continued stress on providing a variety of quality services to consumers. As a business, the agency's success is measured in terms of prosperity and growth. This only happens if quality services are offered that cannot be obtained elsewhere. For the agency, the fact that competition in the local and surrounding communities has arrived makes survival a priority over the next few years. In order for the agency to compete and survive, it will have to change its delivery system, something that is taking place at the present time. But, keep in mind, it may not be changing not so much because it is the right thing to do, but rather because of social forces which it feels is pressuring it into a reactive position.

The fact that other human service agencies have decided to also offer residential services has created distance between themselves and the agency. There does appear to
be "ego problems." As one management-level employee put it:

There certainly is some major inter-agency ego problems now that [name of other agency] and [name of other agency] have gotten into residential services. They really don't know what they are doing and it shows. They should have come to us and asked about things they really need to know as they started their programs (Respondent M-7, 1993).

They never asked how things are done. They need to know about different models so they can offer services to married couples and others. They are confused over options now and we will not be helping them out. They even are telling consumers to not discuss things with us because they are trying to talk them out of our agency and into receiving the same services from them. It's going to get ugly before it gets better (Respondent M-7, 1993).

Because the agency is going to go through some major changes in the near future, the biggest challenge to them will come from different advocates. This will be their biggest hurdle to jump over because parents and other legal guardians often have unjustified fears that are born out of ignorance which accounts for some unrealistic demands and requests. As the same staff member put it:

Now that we are putting together some radical changes in how we provide services, advocates will start coming out. What we need to do is promote more self-advocacy which will allow consumers to make up their own minds. This will help them keep their services ongoing with choices and education (Respondent M-7, 1993).

The Wider Community's Attitudes as External Obstacles

According to Clinard (1974), being labelled "mentally deficient" or being found wanting in mental capabilities carries with it one of the worst stigma known to modern western culture. Scheerenberger (1976) and many others have clearly shown that, as a group, persons with developmental disabilities have never been favored with a full
measure of human respect and dignity. They have always been thought of and treated as if they were something less than human, something significantly different than some norm of human wholeness. Gardner and Chapman (1993) elaborated upon the point of being "different" and being "devalued:"

The distinction between the terms "different" and "devalued" is important. Many individuals are different but not devalued. ....you can deviate from the norm in certain ways and your friends will still tolerate you. However people who have developmental disabilities and are devalued are not allowed to act differently. Society is not willing to tolerate differences in people with developmental disabilities. Thus, people who are negatively valued because they are different must act in a conservative [subordinate] manner (Gardner and Chapman, pg. 46-47).

While not directly measuring obstacles at the societal level, my study, none-the-less, allows the reader to make some connections. For example, it is clear that the "retarded" remain the brunt of cruel jokes in the media and provide examples for parents to show their children "how not to be." On shopping trips, it is easy to see society's resolve to keep members of this minority group oppressed and devalued. The following are just a few examples of the reaction directed towards the disabled when they dare venture out into the wider community. One RPM Aide recounted a story about an incident that took place when his group left a movie theater after having had a good time watching a film:

Our group home consumers and staff decided to go out for a movie one weekend night. Upon exiting the theater, a large group of students had parked and were listening to loud music and conversing. When our group passed these students, many of them yelled and joked about our group, loud enough to where our clients heard what was said about them (Respondent S-01, 1993).

I put the my group in our van and I went back to the kids and confronted them straight-up. I told them it took pretty big people to make fun of people who perhaps were less fortunate than themselves. In return, they
yelled and cursed at me, leaving no mistake in my mind that they could have cared less about me or someone's opinion about what they had done. I felt sick. Young men and women feeling that it was ok to do what they had done. I went inside, got security, and they called the local police. The police showed up and told the kids to get out of there. It was a sad night and one I'll never forget. What are we doing to instill such values and attitudes in our young (Respondent S-01, 1993)?

Likewise, another RPM told of an incident while out shopping:

We stopped inside the mall for a bit to eat. My girls and I ordered pizza and were waiting for it. Three women kept staring at us, pointing and laughing at my girls. I'd had enough. I could tell Mary [not her real name] was upset because she started pulling on her hair. This is what she does when upset. I knew she had caught on to what these stupid women were doing (Respondent H-12, 1993).

Well, when we finished, I got up and threw the trash away in a can next to them. I then bent down and told the one woman who was pregnant that many years ago when Mary's mother was pregnant with her she did not realize that her baby daughter was going to be mentally retarded, and that I hoped her baby would be alright since I wouldn't want her baby to someday be humiliated in public by having a group of women laugh at her. The pregnant woman and the other two stopped smiling right away. I walked away feeling mighty good, but sad too. I just can't believe how cruel people, grown-ups even, can be. It's beyond me (Respondent H-12, 1993).

Recently, the manner in which members of the wider community criticize and joke about the persons who struggle with disabilities was highlighted when one of my own consumers held a pizza party for his "normal" friends from his place of work. Brad had invited several of his non-disabled work mates from one of the local restaurants to stop over for pizza. A night was decided upon, pizza was ordered, and his friends showed up. Initially, I was happy to see that Brad was able to initiate such an event, and happier yet that Brad's non-disabled work mates accepted his invitation. However, what happened shortly after the evening commenced is difficult to put into words. I
interviewed Brad and his roommate in order to capture the event from their perspective.

They stated:

It [the evening] went ok. Four guests showed up. There was me and Bob. I invited Mike, Robb and Kathy and Erin. They all work in the deli with me. The pizza come and I paid for the pizza at the door and I set them on the counter. Robb brought a twelve pack of beer. Then they all come afterwards (Respondent C-1, 1993).

We were sitting at the table and we were talking about work and me getting a diploma. Mike said he didn't want to hear about it. And, ah, I served them pizza and they got the beer themselves. They were sitting at the table and laughing about me and Bob and my wife [Brad is married but doesn't live with his wife] (Respondent C-1, 1993).

They was saying. They was making fun of Bob when he was getting up [Bob has Cerebral Palsy and had very bad gross motor skills]. They said....they were laughing and giggling and making fun of Bob. I could see them making fun of him at the table. And then when Bob asked Mike about working at the deli they started laughing about it. They thought the Bob working at the deli was really funny (Respondent C-1, 1993).

Bob tried to show Mike pictures of his family and Mike just kept laughing. Bob didn't think it was too smart for Mike to be laughing. [Bob had asked Mike if he thought he could get a job sitting down and folding silverware into napkins in the deli]. They all started laughing when Bob asked Mike about a job in the deli. They all started laughing (Respondent C-1, 1993).

When I served them pizza Bob was talking, and the guests were all laughing and had funny looks on their face. They were laughing and giggling so hard they had to cover their face by their hands. One guy had to put his hat over his face because he was laughing at us to much. It was bad. Man. It was bad (Respondent C-1, 1993).

These gentlemen felt very bad about having their nondisabled guests sit there and eat their food, only to make fun of them for being disabled. Again, the degree to which these nondisabled persons felt that it was permissible to make jokes of these people in that setting goes beyond anything words can describe. It does give insight into how
consumers are still considered different and devalued by society. Considering the attitudes reportedly held by staff, the conservative opinions about the sexual behavior, and the amounts of abuse and excessive social control by the agency staff, it all reflects a larger perception of the consumers which originates from and is perpetuated by the wider society.
In part, my research was guided by the assumption that the more normalizing the residential environment, the higher the quality of life would be for consumers. My feelings on the importance of offering normalized residential settings to consumers was captured by Landesman (1987), who stated:

....the popular social policy that endorses smaller and more home-like living units, higher staff:resident ratios, greater individual privacy and space, interdisciplinary planning for the habilitation of each resident, and the provision of daily training or education in structure situations. According to this policy, quality of life for almost all residents should be closely related to how well these objectives are met (Landesman, pg. 86).

For example, in a traditional group home setting, staff-consumer ratios were low. On average there were 2 staff for 11 consumers. This would not appear to be accommodating to the many individual needs for care and attention that materialize in these homes. In addition, as the spatial analysis has shown, many rules or house guidelines must be put into place, not so much to stifle individuality, but to see that the house runs smoothly while meeting the basic needs of the inhabitants. Feelings and frustrations over group home life were discussed by several of the respondents who took part in this quality of life phase of my study. Several of the respondents' statements appear below.

Robert reported:

I use to live at [name of group home]. I liked it. Except with [names of RPMs]. I had some problems with them. They wouldn't let me go out when I want to. I had to get my laundry done first and get my room clean first. (What rules didn't
you like?) Go to bed at nine o’clock. Take a bath. Shave. I haven’t shaved today yet (respondent feels beard growth and laughs out loud). They wouldn’t let me go to (name of grocery store) cause it was too dark and late. I was upset. I wanted to drink a pop or something and I would get angry. (What would you do when you got angry?) Throw stuff in my room.....nobody saw me in my room (Respondent C-14, 1993).

Ruth captured the frustration and how they felt compelled to break the rules:

I liked it at [name of group home]. The rules I did not like, but I got through it. They had a curfew. That was one [rule]. You couldn’t go outside the doors after curfew. (Did you have an alarm system?) Yea. It made me feel strange. (Like a prison?) Yea. You had to sign out. When you went to bed you had to go in the wings and shut the doors. (Did you ever break the rules?) Oh yea. I used to catch guys coming out of windows (Respondent C-10, 1993).

It was good in a way and it was bad in a way. It taught me how to live on my own and, um, I already know how to clean and everything. But it made me learn life. I learned social skills. Then I learned how to get along with people. I used to be shy. I used to stare at the floor all the time. I went and tried for to get [specific training certificate mentioned] and I made it! I then went to work at [name of company]. I then left the group home.....I ran away (Respondent C-10, 1993).

I ran away because they grounded me all the time. They thought I was seeing this man, and he would come by window and try to come in, but he didn’t come in. But they thought he did, so I got grounded for nothing...for just talking. And then the man took off with another girl from the group home. Later, he broke up with that girl and came back to me (Respondent C-10, 1993).

Some of us girls had fights. It was all women where I lived. It was tough. One of the girls that was there had booze and we got drunk and we weren’t suppose to. The girl sneaked the booze in, and we mixed it with some orange juice. We did it right in the living room, but the houseparents were in their own room and stuff. We never did get caught (Respondent C-10, 1993).

The grounding, I mean. I know we’re grown and stuff. And the phone usage, 10 minutes on the phone. I was kinda disgusted with it. But it was teaching me, I guess. (Didn’t you ever complain to your houseparents?) Yep, and (name of houseparent) would come in and wanting to know everything about your life. I would get upset and start crying and leave
the room. When I was living there, I wouldn’t hardly talk because I didn’t want to get into trouble (Respondent C-10, 1993).

Further, one female respondent talked about a sad side of group home life. She reported:

Yes I got frustrated. We had many rules. Curfew. I was grounded all the time. One time I wasn’t done with the water, so they shut the door on me and didn’t even answer or say anything to me (Respondent C-9, 1993).

I enjoyed it most of the time, when (name of houseparent) wasn’t around. When (name) was around I hated it. He’s such a grouch. He didn’t treat me too good. He used to just yell at me a lot. He never wanted to talk to me. He was just really mean. I just don’t like him. He was gross with that big belly. I don’t like one thing he did....when he was sitting on a chair, he had his legs spread apart and you could see everything. You could see part of his penis from his pants. I didn’t mean to stare, but I did (Respondent C-9, 1993).

Finally, one male responded this way when questioned about group home life:

Life in a group home was boring. I couldn’t do what I wanted to do, no freedom. I couldn’t sleep when I wanted to sleep. I couldn’t listen to my music loud when I wanted to listen to my music. I had something to do every night, no free nights. I had chores like mopping, putting dishes away, setting the table (Respondent C-22, 1993).

The rules there [at the group home] weren’t all that great. I had to go to bed at a certain time. You had to watch t.v. what everybody else wanted to watch. You couldn’t go out into town just when you wanted. You had to be back at a certain time (Respondent C-22, 1993).

(Were you treated with respect?) Well, it wasn’t really respect. I got my t.v. taken away when I was sick. They said they didn’t want me to lay in bed all day and watch t.v. I got my stereo taken away a lot of times for playing it too loud. I’m that way with my music. Well, I don’t do it anymore. I put my headphones on or something (Respondent C-22, 1993).

(Did you ever get treated unfairly?) Yea. I fell asleep in the t.v. room and they punished me and told me I couldn’t watch t.v. for a week or two weeks. Every time I fell asleep, they kept jacking it up more and more. The first time was a verbal warning. They gave me two verbal warnings. Then when they caught me, they kept jacking it up a week. It made me feel like, hey, if there was another person who fell asleep,
they wouldn't do anything to them. It just kinda picked on me, nobody else. I didn't like that (Respondent C-22, 1993).

In contrast to reports about rules and punishment at traditional group homes, respondents felt that their present apartment living environments offered much improved conditions. After having experienced the structure of group home living, this came as no surprise. When asked, even jokingly, respondents vehemently denied ever wanting to return to group home situation. One respondent told me that drop-in advisors use the threat of returning to a group home environment as a way of getting consumers to respond to directives.

There is always a certain amount of transition that goes on when a "group home person" enters a new, less structured environment. When consumers have been relocated to less structured environments, they will begin testing the waters of their new residential settings and exploring the potentials of newly discovered liberties. There is a period where consumers still rely heavily on behaviors and routines suitable for group home life; what is still most comfortable for the consumer. Most of the time this includes the need to take part in only "group" social activities, the need for assistance in most meal planning and preparation skills, and a general reluctance to make and travel to medical appointments independent of staff assistance. Normally, these transition behavior patterns are due, in part, to a temporary lack of self-confidence, not from a lack of ability.

Moving to a less structured, more normalizing residential setting had positive consequences for all 24 respondents. In no case did respondents report that they wanted to revert to group home living, and, with only few exceptions, did they indicate that they
would not feel willing to move on into even more independent living situations. Some of the comments made about their current independent living arrangements were as follows.

Jeremy reported enjoying his new found freedom:

Well, life's a lot better. I can come and go when I please. I don't have to write my name down on a piece of paper and let people know that I'm going out. I don't have to be in at a certain time. Makes me feel a little better about myself. One of my goals is to get married to [name of girlfriend] and raise my little baby. Get a house. Buying. It's one step next to a house (Respondent C-7, 1993).

Sharon expressed her joy at more independent living as follows,

I love it! It's just much more fun to be on your own, with just a little bit of rules. (What rules?) Mostly that you just have to call if you took your pills. Otherwise you're free to come and go as you want as long as you tell them how it went. Otherwise, I am free to go as I want. I feel happy, and when I get my own house, I'll be all by myself (Respondent C-24, 1993).

But, this is not to say that all reports were positive. While new found freedoms were a matter for celebration, the social demands surrounding increased, more complex social responsibilities and personal accountability quickly confront consumers. For example, there are bills to pay, the need to demonstrate social skills in a variety of settings, as well as new requirements in the areas of medications, safety and security conscientiousness, personal hygiene and room care, as well as the need to show an honest effort at needing less and less staff involvement in decision-making situations, and the challenge of reducing attention-seeking behaviors. Some of the frustrations voiced by respondents include the following. Mary demonstrates the challenges and frustrations of apartment living:
Yea, I'm happy. It's just I kinda wish I could get off of [agency's name]. I mean [the agency] is fine. There's just too many rules. (Rules? Here?) Oh yea. We have rules. We used to have curfew, but no more. I mean rules that have to do with our drop-in advisors. My worker coming in here all the time. They don't like [boyfriend's name] here. They want him to stop drinking beer. He doesn't drink that much, but he won't stop (Respondent C-10, 1993).

At first, they didn't want me going with him. They thought he was using me. He has a job and we do stuff for ourselves. My worker only comes twice out of the week now, just to check up on me and make sure things are ok. Sometimes my drop-in [name of advisor] breaks the confidentiality between us. I tell her she's not supposed to be doing that. She tells me stuff about other girls. She can get burned doing that. I know she tell others about me because she tells me about others. That's why she shouldn't tell (Respondent C-10, 1993).

Jan discussed the reality of running out of money on her budget:

Life in the apartment complex was ok. I like the apartment. The hallways were dirty and looked terrible. I didn't like having to go out into the hallways to do wash. I asked them to put a washer in my apartment, but they said they couldn't do it. When I ran out of quarters I had to do without. (How much did you get a month for laundry for you and your baby?) They give 30 dollars a month (Respondent C-18, 1993).

The place I'm living at now is nice, but I don't like the carpet. The floor is cold and hard and I like to sleep on the floor. The neighborhood is quiet. Nice neighbors. One even offered me a ride to the gas station. It's nice and quiet unless someone drives by with their stereo loud. Now, I'm happy with my living condition. They're good (Respondent C-18, 1993).

Randy also expressed pleasure in his living arrangement, but spoke of money problems:

I would say that I like it right where I am at. I wouldn't want to think about going back to a group home. Honest. I would not want to go back after putting up with what I had to put up with. Not only the rules, but house-parents yelling at you and stuff like that. (What would they yell at you for?) Oh, for not doing your chore right. But they never yelled at me for that. (What did they yell at you for?) Well, they'd get a little discouraged because sometimes I didn't get home till a little late. Hey! On my job, I can't predict the time (Respondent C-13, 1993).
(What about the amount of money you get now... spending money?) Well, I get $12.50 now a week for an allowance. When I was living at a group home, I got like $12.00. That's all. Sometime, it was $10.00. Well, I'm satisfied with $12.50. I can go out to the mall with $12.50, buy a hamburger for lunch and have some money left over. Sometimes, I go to the drug store there. They have a pop machine for .35 cents (Respondent C-13, 1993).

Finally, Ruth was clearly frustrated over the lack of spending money:

What shopping? I don’t have the money to go shopping. My supervisor handles my money. She gives me $5.00 a week for laundry in quarters. I get $7.50 spending money on weekends. For a total of $12.50 a week. It kinda makes me mad, they handle all my money. I can’t buy things I want, like for my baby daughter. I have to budget my money wisely and I’ve got laundry to do. (What do you spend your $7.50 on?) Oh, we [Ruth and boyfriend] buy a pop. Movies are $5.00. Usually, we just go to the "Y" [YMCA] because we have a membership there and it's free. We just tell them who we are (Respondent C-2, 1993).

(What would you do if you have more money?) Spend it on my baby. I like to shop for her a lot. Me and [boyfriend] went to K-mart the other day and bought her a little outfit. My boyfriend only works part-time, and they need him in the field off and on. He helps out sometimes [with money] when he can afford it. He has a car right new, but it's in the garage (Respondent C-2, 1993).

One of the biggest challenges facing consumers who live in independent residential settings is transportation. Only one of the respondents interviewed had direct access to an automobile for his transportation needs, while two other respondents had access to an automobile through boyfriends. All of the other respondents either had to rely upon the local bus system, which only ran six days a week and on a very limited schedule, or on the kindness of staff, family, and friends. Sundays and each day's evening hours appeared to be the biggest challenge for consumers since no public service was available. Considering how many social events required transportation at those times, most
consumers reported having to pass on such opportunities. Some of these challenges and subsequent frustrations facing consumers were captured in the following passages.

Joe talked about his transportation problems:

One of the biggest challenges in living out here is getting around in the winter time. Transportation. I have to walk up to the bus stop. Up to the [gives location], about five blocks away for the early busses we do. There's a stop out here on [name of street] for other busses. I have to be to work by 7:00 a.m. (Respondent C-16, 1993).

(What about other times you need transportation?) Cabs and friends. Once in a while I can afford a cab, but they're expensive. Not often. It costs $8.50 one way. I ride my bicycle sometimes, too (Respondent C-16, 1993).

One time I needed transportation and couldn't get it. It was in the middle of winter, so I bundled up and went to get them [groceries] on foot. Sometimes my drop-in advisor picks me up at work sometimes (Respondent C-16, 1993).

Another respondent, Joel, appeared to just take the lack of transportation in stride:

I take the bus system to work and bring it home. I got a bus pass I use. (What about Sundays when there are not buses?) Oh, I just, if I want to and if its nice outside, I just go for a walk. Otherwise I just stay inside if it is raining. I have a bike (Respondent C-6, 1993).

Evaluation of Residential Settings and Quality of Life

In general, the consumers I interviewed were happy to be living in less structured environments. There is no doubt that a certain status hierarchy exists within the residential settings for these people. The consumers with whom I talked felt that group home living and waiver home environments were things to be avoided. Apartment living, in any form, was considered far superior to any of the other forms of residential service options. No consumer actually owned a home at the times of these interviews, but one respondent reported that she was in the process of purchasing a home due to receiving a
large back payment from the Social Security Administration.

It is difficult to say with certainty whether or not consumers really enjoyed a high quality of life. But that statement is heavily biased from my own perspective. When looking at residential settings from an individualistic perspective, I believe that most of the consumers felt that their living environments were satisfactory. They expressed pleasure in that they had more freedom than in a group home, that there was some ongoing training programming, that their safety and security needs were met, and that they would not like to return to group home living. However, as in any situation, there is both good and bad, and, for many consumers who resided in more independent settings, there remained many trials.

For example, money management and budgeting were major problems. The fact that consumers must struggle, in some cases desperately, to make ends meet pointed to a rather significant structural problem. According to agency staff, the county government and the Department of Human Services (DHS) played key roles in determining how much, or how little, money consumers can claim as their own spending money, often referred to as "allowance" by both staff and consumers. This complicated process begins when the agency submits their bill to the local county for providing residential services to the county's consumers. Based upon a sliding-fee scale, if the consumers make over what DHS has set up as allowances for living expenses, the consumers must repay the county a certain percentage of the cost incurred for those services. Table 9, below, presents a breakdown of such allowances made by DHS.
The problem with the amounts presented in Table 9 is that it is becoming increasingly difficult for the agency and staff to locate goods and services for their consumers which fall within these monthly spending limits. The only exception to this was the amount allowed for rent. For example, having only $150.00 to spend toward food does not leave much room for personal preference. Consumers are forced into purchasing the cheapest, least expensive food stuffs that fit their individualized menu plans. Items such as cookies, ice cream, frozen food items, and many meats are cost-prohibited and can only be purchased with careful planning, or "going without" in another category. The nutritional content of many meals may suffer because consumers may wish to spend their money on specialized food treats rather than concentrating on wholesomeness of products. When this happens, consumers' health may become jeopardized, or they may elect to not eat three balanced meals a day.

Table 9. Breakdown of Monthly Living Expenses for Consumers in Dollars.

<table>
<thead>
<tr>
<th>Expenses</th>
<th>Amounts Allowed</th>
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<tbody>
<tr>
<td></td>
<td>Shared</td>
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<tr>
<td>Housing</td>
<td>300</td>
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<tr>
<td>Food</td>
<td>150</td>
</tr>
<tr>
<td>Utilities</td>
<td>100</td>
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<td>Transportation</td>
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</tr>
<tr>
<td>Telephone</td>
<td>13</td>
</tr>
<tr>
<td>Clothing</td>
<td>20</td>
</tr>
<tr>
<td>Medical</td>
<td>100</td>
</tr>
</tbody>
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Cost of utilities is an amount that often cannot be controlled as much as one would like. For example, some consumers suffer from poor circulation due to medical
conditions requiring more heat in the winter time. Additionally, many apartments are located upstairs in buildings which traditionally heat up more in the summer and require more energy for air conditioning. The transportation allowance is one example of how "out-of-whack" these limits have become. For example, most of the consumers had a need to purchase monthly bus passes for which they received a price reduction due to their disability status. The county allowance restricts payment for this monthly necessity at $18.00. However, even after taking into account the consumers' discounts, the costs for bus passes still exceed these limits as consumers pay $25.00 for a standard ticket and $40.00 for curb-side service services. Unfortunately, since many of the consumers had significant gross motor skill loss, they were required to purchase the more personalized, more expensive bus services.

With respect to telephone service, the county allowed only $13.00 for shared expenses, or $26.00 for those living on their own. The average, basic service cost for consumers was $23.00. Many have additional services added to their accounts for things like line repair and long distance restrictions which increased the cost of their basic service even more. When you add any long distance calling on top of these basic service prices, it is easy to see how the $13.00 for each individual in a two-bedroom apartment was not adequate. In some cases, staff have had to request that long distance service be discontinued because some consumers enjoyed speaking to family and friends, but had difficulty conceptualizing and differentiating between local and long-distance calling expenses.
The clothing allowance of $20.00 is another area that is wholly inadequate. Most consumers are hard on clothing, and repairs and new purchases were a constant concern for staff. In addition, many of the consumers' employers required them to purchase certain types of clothing in order to meet uniform guidelines. In the current retail economy, $20.00 was an insufficient amount when it came to purchasing three sets of underwear, let alone dress shirts, slacks, shoes, or more formal wear. Most consumers are forced to depend upon "hand-me-downs" from family and friends, or shop at the local used clothing outlets where they attempt to find suitable clothing. Finally, it is worth noting that the DHS does not provide any allowance for furnishings for apartments. Consumers, once again, must rely upon the kindness of others, or save up their spending money for a trip to the used furniture store in order to find better pieces. Finally, while allowances varied, most consumers receive between $30.00 and $70.00 dollars each month for "free spending" cash, i.e., about $25.00 every two weeks for their personal spending money used for movies, snacks, shopping, VCR rentals, and so forth.

It all seems so self-defeating. The more money consumers bring in through their efforts at some competitive employment job, the more the county seeks to recapture. There appears to be very little incentive to work harder, longer hours, or, for that matter, to work at all. One consumer expressed his frustration over working hard, but not being able to afford some basic things for his apartment:

I would like to buy a chair, but I can't afford it right now. Some new pictures for the wall, .....paint the apartment. It's got holes all over the place. We even got a hole in the bathroom where the water comes out....inside the water heater closet. Mice come in there. I'd get some
.....a few neckties and a set of suspenders. I don't have enough money to buy the things I want to buy (Respondent C-1, 1993).

However, consumers are not only required to have some form of day program if residential services are offered, but they, like everyone else, are socialized to define themselves according to their occupation. Even though the jobs most consumers get through competitive employment are part-time and stereotypical with low wages and minimal or no benefits, there is a certain amount of status that comes from working outside a Rainbow Industries location. Rainbow Industries is a local employment service agency established to train and employ individuals with developmental disabilities. When it comes to quality of life, the employment setting is viewed as another key area to examine, and it is to that area that I now turn.

**Employment Opportunities and Quality of Life Issues**

Like any so-called "normal" person, individuals with developmental disabilities receive a lot from their jobs. First, they do receive an income in which to take pride and which offers them some hope of purchasing a few items for which they have a need. Secondly, it provides them a certain portion of their self-concepts. It helps them to define themselves as it does for "normal" people. It offers them status and prestige within their community and it helps to develop self-esteem and provides consumers with something tangible from which to derive and direct personal goals. Finally, and in contrast to the positive benefits, it also means that consumers can become anxious over their jobs as work can become a source for significant stress. Often the types of work done is very physical and labor intensive.
Most consumers interviewed in my study began their work lives with an evaluation period at Rainbow Industries. Rainbow Industries offers day programming within their own factory workshops and they assist consumers in training for and locating competitive employment at various retail outlets within the community. The conditions offered in the work environment can impact anyone in either a negative or positive fashion and for those consumers who had experienced work at Rainbow Industries, the evaluations were mixed. Some of the work was extremely routine, menial, loud and, depending on the season, very hot or extremely cold. Accounts of work at Rainbow include the following.

Joel, a worker at Rainbow, offered his feelings about his work:

Well, number one, people there are total idiots. I'm not talking staff, I'm talking residential employees. There's one person there who repeats stuff over and over and over again. It gets annoying. Then, the floor supervisor that I have sometimes throws the job I've done back at me when I studied the job, done the job before - like cardboarding - I know how it's suppose to be done. If I don't know, then I ask. Well, she [his boss] comes back and throws the work on me and tells me that I'm doing it all wrong, when I'm doing the job the best I can (Respondent C-22, 1993).

I've been called an idiot before by staff [at Rainbow]. I'm suppose to wear a back brace at all times and they don't like me wearing a back brace. They say that my back don't hurt. Staff at Rainbow don't like me wearing it. They say it keeps me from working. They say it's in my way. It's written on paper now. If they tell me to take it off now, I walk out of the building. I punch out, get my stuff, go to my doctor, my advisor and tell them what's going on. They check it out and I go back to work (Respondent C-22, 1993).

Mary also discussed her work at Rainbow:

I've hung clothes on hangers for 19 years. I hate it! I hate my case manager! Working at Rainbow and having [name of manager] as my case manager... ...I just wake up in the morning and ask, Do I have to listen to her? She bosses me around. She's grumpy all the time. If I say anything, she sends me to her chair to sit there until she comes back. She even punched me out on
the time clock because she didn't like the work I was doing. She picks on me. (Respondent C-9, 1993).

Sometimes when I call her up saying I really don't feel good, she forces me to come to work. I don't like her. Quite a lot of clients in there don't like her. She's a crab. I could probably get another case manager if I wanted, but there's another one [case manager] in there I don't like. So I sit and suffer (Respondent C-9, 1993).

I don't mind hanging clothes up and stuff. It's kinda fun when you can talk to your neighbor next to you. But what I can't do is the crates. I can't bend over because it hurts. I had a [medical condition] and it still bothers me. I told her [the case manager] I hurt, but she just got mad and sent me to her office (Respondent C-9, 1993).

Steve expressed concern over how Rainbow impacted upon his personal life:

When I worked at Rainbow I didn't like it. They got a lot of rules. When I get there I start at 8:00 and don't get done till late that night. Long days! Didn't know when I could get off and didn't know when I could see my girlfriend on weekends. (Was it frustrating for you?) Yea. Now I can come and go when I'm not working (Respondent C-13, 1993).

Frustration over the job and staff were also voiced by Robert:

I was a jack-of-all-trades there [at Rainbow]. I was in electrics, furniture, on dock, on can truck. (What did you like the best?) Dock. (And the worst thing?) Can trucks. The trucker complained about everything. And on top of that, he would tell me things that was none of my business. About the way the place has been operating over there at Rainbow with the can trucks. I couldn't take it no more. Sometimes I'd call in sick just to get away from him. They thought I was drinking all the time. My boss treated me like he was the boss and I was the guy who'd go out and dig up the shit. Something like that (Respondent C-8, 1993).

Many consumers had applied for competitive jobs, but either they did not have the skill level required, or Rainbow did not have the funding to meet the particular training demands. Many consumers felt that Rainbow did not offer them what they wanted in employment opportunities. It was interesting to note that several consumers viewed
competitive employment as having a higher status attached to it since it was perceived by consumers as "more normal." One consumer captured the importance of this when he commented about his job as a dishwasher at a local establishment:

I hated Rainbow. I felt put down and I hated it. I didn't like working with those people. They'd drive me crazy. It was the same thing day and day. I hate just sitting there cutting pieces of cloth like this and like that. It was boring and when I tried to change jobs I always got told to wait my turn. Be patient they kept telling me (Respondent C-23, 1993).

(But you did get out, didn't you?) You bet! Man was I happy to get out. I love my job. I get to work at my own job now. I go to work like you do. It's my own job and I work with college people. They treat me nice and we have good times there. They like me and I do a good job for them. I don't mind it hot and sticky because they know I do a good job. They tell me that (Respondent C-23, 1993).

(How's it make you feel now? Would you go back to Rainbow?) No way! I will never quit my job. I love it. I do a good job and I get a regular paycheck. I give it to [name of RPM] every two weeks [rubs hands together as if real pleased with self]. I make more money know than I did before. I am getting more and more hours now. They call me in when some guys don't show up for work. I like it because I feel good when I'm at work (Respondent C-23, 1993).

Many consumers who worked competitively reported only a few problems. Most of which had to do with misunderstandings about work expectations and once their job coaches explained things and assisted them in their new assignments, things went smoothly. Consumer "staffings" also took place regularly at these competitive employment sites which allowed the consumers' managers or immediate supervisors to be present and to take part in the meetings. During these meetings, concerns were expressed and remedial action, if required, was determined and plans of action were developed and agreed upon by all present. Most consumers reported very favorable
impressions of work in these "real world" environments. The following passages capture some consumer thoughts about their jobs and how they felt about themselves because of their work. Sam reported that his competitive job:

Pays more better. I got retirement plan, too. I got my 401k program, medical and dental. Basically, I work 5 days a week, 8 hours a day or longer. I definitely enjoy working by myself. I'm on my own, one boss. We touch bases during the day and he tells me what needs to be done and I check with him if there's a problem in a certain area. I do have a career there (Respondent C-16, 1993).

Mary also talked about her job experiences at a few of the local fast food restaurants:

My first job was at [name of restaurant]. I was there about a year. I bussed tables and cleaned up the dining area. I prefer to work in the back because in the back they have to be really fast. I went to [name of another restaurant] after that. It's much different there. There you're around college students. Sometimes it makes me nervous because I feel like they might say something to me. Make a cruel remark. It hasn't happened, not even very likely. Sometimes I feel like a college student. Sometimes, I do (Respondent C-20, 1993).

When I first started there I thought I'd mainly do salads. Now, I've been trained on different stations. The one I mainly do is drinks. Not every day, it depends on what they put me on (Respondent C-20, 1993).

I go in at 7:00 in the morning. That's kinda difficult. I get there by bus, which means I get up at 5:00 to catch the first bus. It stops down here on [name of bus stop street] (Respondent C-20, 1993).

Finally, Ted talked about his job in a local deli:

Yea. I feel good about working at [name of business]. Lots of people wish they could work out there and get a job. I like helping the customers out. I tell them.....they tell me 'thank you' for helping them out. I have a little sign on my name tag that says, "May I help you?" I would like to just work at showing them [customers] where things are at. I like to learn to bag groceries. (What is important in your job?) Well, being on time, checking in on time, going to my station and cleaning pots and pans, and keeping......[pause] (Respondent C-1, 1993).
One thing competitive employment did for consumers was to provide them with the chance to realize one of the major goals – employment that broke with tradition. It gave them the opportunity to function within a "normal" work environment, and to crossover and socialize within a normalized setting. It also provided them with a platform from which to form new dreams and aspirations, including the development of long-term work and personal goals. A sample of these individual work and personal goals as expressed by consumers included the following:

I've had dreams. I'm a very good singer. Through college activities, I've met a very good singer. He can spot that I have a little bit of talent. I'd more or less like to sing, maybe professionally. Maybe I can become better on my clarinet and play for work (Respondent C-4, 1993).

One of my dreams is to drive a semi-truck on the road. I'd like to work at [name of establishment]. Factory work. Something like that. Piece work. I'm trying to get my license for a car right now. I got my license taken away for six years for drinking and driving when I was a teenager. I can get it [the license] back if the state would send me a letter saying it's ok. I'm still waiting for them to send me the letter (Respondent C-7, 1993).

I would like to be a writer or restaurant manager. I would write books about my life. Like what we're doing. I always liked to write. I love to write. The only problem I have is with my spelling, commas, periods, and question marks and stuff. I would like to get a computer. I don't have the money now. I got a "C" in word processing at school. I sure want to get myself one. I sure want to get one. Cause I sure want to get one (Respondent C-18, 1993).

Well, everyone says I'm a good cleaner. I've thought about maybe being a cook someday in a restaurant. (Have you ever tried to get a job in a restaurant?) No. I haven't gotten that far. I haven't tried that yet. Maybe in the future, probably. If I get too tired of Rainbow. That place is yuck (Respondent C-5, 1993).

I would like to work at a nursing home. I could do the work fantastic, but I couldn't chart down stuff and put the person to the name. But I could do everything else. They helped me there for a while, but they couldn't
do it all the time [at a previous nursing home job]. I would like to work at a nursing home. But, my reading is way low. I can do my math. (Respondent C-10, 1993).

and finally:

Well, I'd like to make more money. Maybe I'd work in the flowers.
I like flowers (Eich, 1993).

In general, most of the consumers interviewed in this study felt very positive about their work environments. I know how important these competitive jobs are for consumers. In my own work, I recently took a consumer (Jack) to a job interview at one of the most popular restaurants in the community. Jack was excited about the interview and for days in advance could speak of hardly anything else. He was already employed at another job, and this was to be his second. The dishwashing position for which he was to interview was more complicated and demanded a certain level or reading and spelling skills. Unfortunately, Jack did not possess a high level of skills in those areas, but he still insisted on at least getting an interview. After Jack's interview had concluded I was called back to the interview room and informed that he would not be offered the job. Right or wrong, management felt that it was better if I was the one who gave Jack the bad news. I waited until we were outside and then I stopped in front of the advertising sign and told him he did not get the position.

Jack was so upset by the news that he became emotionally shaken and physically upset. I explained that the job required him to change the reader sign that stood before us. I asked him if he would have felt comfortable doing this and he told me no, that he would have needed help. He then understood that the job required more than his skills
allowed. A few weeks later, I heard that Jack applied and got a second job at another restaurant. The first time I saw him after he got the new job he explained to me just how great he felt about having two jobs and being able to bring home more money. He told me that he hoped that he could afford to buy things for his apartment. Little did he know that his efforts were not going to make a significant difference due to the fact that his client participation would increase.

Jack's case is typical for many consumers. The increased self-esteem was apparent. Jack was clearly walking around on "cloud nine" and enjoyed pointing out to those around him that he was one of a few consumers who had two competitive jobs. I am convinced that Jack wanted the second job for two reasons. The first is that he loved to work. The second reason was more social. Jack did not have much or a social life outside of his associations with his fellow disabled peers. For that reason, Jack loved to work because he reportedly enjoyed the chance to increase his social interaction. This type of community integration provided him with yet another opportunity to try to form secondary groups whose members help validate his self-worth. Community integration is vital to consumers' success and well-being and it is to that area of the quality of life model that I now turn.

Community Integration, Social Life, and Quality of Life Issues

Making more normalizing residential settings available for consumers goes a long way in promoting a higher quality of life. Likewise, making it possible for individuals with developmental disabilities to earn wages through work within the wider community is another feature important to their quality of life and these things appear to be easily
accommodated by members of the wider society. I believe that it makes employers feel good to hire, whenever possible, developmentally challenged persons. More important, living and working among the wider community allows individuals with developmental disabilities to be "out there," to be seen by members of the wider society. However, based upon my own personal experience in working with the consumers, I believe that is where the normalization process fails and falls short of its goals. That is, individuals with developmental disabilities are not given the opportunity to network and develop friendships that might otherwise meet their needs for friendship.

The reasons for this are many. To begin with those labelled by society as "disabled," "retarded," or "handicapped" have been devalued, and, as Clinard (1974) pointed out, no personal situation is worse than being found lacking in the area of cognitive ability. It is on these people that the rest of society's members place the worst stigma. Because of this, individuals with developmental disabilities are often thought of as less than human, and as good examples of "how not to be" as they are made the brunt of cruel jokes and stories. In effect, these individuals really take on the label of disabled, of being different, of being needy and, thus, often willingly appear subject to vast amounts of social control. Given the fact that this type of social conditioning goes on from birth through adulthood, it is no wonder that such persons may begin to think of themselves as less than "normal."

Because such labelling is out there beckoning the disabled, it is very difficult to develop and sustain meaningful friendships with people who are not disabled. There always appears to be some sort of imaginary line drawn in the sand over which neither
disabled, nor nondisabled, persons dare cross. For example, while it is quite acceptable
to take time out of the day to take a person who is disabled to a sport event, or out for
coffee and pie, the same person may feel awkward inviting the consumer to a party.
When it does happen, often the individuals with developmental disabilities are not fully
included in conversation or activities. Even going out into the public with persons who
are physically or mentally challenged can be a challenge for staff to not react to the
looks, the pointing, and the laughter directed toward them. Because of the fears and
uncertainties, persons who are developmentally challenged are often bound to a limited
social life.

Normally, the social gatherings attended by consumers are segregated, including only
other consumers and staff. For example, recently a dance sponsored by a volunteer
organization included invitations for only those persons who were receiving services from
the residential service organization. In the summer, there is softball for consumers, but
only in a league that is exclusively formed for participants who are disabled. Only on
select evenings do others come to join in the fun, (e.g., local celebrities, college students,
and so forth), but participation is reportedly ridiculously low and ineffectual when it
comes to meaningful networking.

Consumers who live in more independent settings often complain of loneliness and
feelings of social isolation. It is one of the most serious, often-voiced frustrations and
often leads to bouts of depression. The following statements show just how far these
feelings can run. One independent apartment living female, Sandy, discussed her social
life:
Free time? I watch my VCR movies. When I'm not watching them, I do my laundry. I see my boyfriend on Wednesday, and every other Thursday, and on Saturday. (Would you see him every day if you could?) No. (Why not?) I don't want to break the rules. (If you could forget the rules?) Yea. I would see him everyday. You don't want to break the rules though. I'd be in trouble, talked to in the office (Respondent C-5, 1993).

(What makes you sad about your free-time?) When my brother don't come to see me. They come over to my mom and dad's house and they visit there. It makes me sad. I think they have more time to go out some place than come over and see me (Respondent C-5, 1993).

When asked about nondisabled friends, one female respondent, Beth, stated:

I do more things with disabled friends. (How many times during the week?) Sometimes four times a day. (How many friends do you have outside of the agency?) Two. (Do you ever do anything with them?) Nope, different. Nobody. (So all your friends are with the agency?) Yup. (Would you like more friends than you have now?) Yea. More friends to do things with (Respondent C-28, 1993).

(Are you happy with your social life now or would like to change it?) Probably change it. Go to movies more. Country, musicals. Old and new movies (Respondent C-28, 1993).

Another women, Janet, responded this way about her free time:

My free time? I stay by myself and read. I took up reading again. My other leisure time is watching t.v. and trying to write. I'm not really satisfied with my freetime because I have no person to spend free time with. I'd like to spend more time outside the apartment, in parks, in the town. I'd like to take a trip to Texas, take my boyfriend with me. I'd like to go swimming, fishing, but I don't like to gut the fish. I won't ride in a boat, though (Respondent C-15, 1993).

A male consumer, John, described his social life like this:

I go home and watch my VCR movies - I'm a fan of (movie star name). (What's beyond t.v. and movies for you?) That's it. I'm watching t.v. or going to bed to sleep (C-7, 1993).
And yet, still another female, Judith, echoes such activities:

I got cable and sit around and watch t.v. Read a book. Play with my puzzles. Or go out and walk the hallways or go outside and walk outside. I have fun going out and walking. (What about your family and visits to you?) My mom’s dead, my dad’s dead. My stepmother don’t have a way to get up and see me. My sister sees me once in a while. (What about friends besides your boyfriend?) Nope, I don’t have any friends. It makes me feel uncomfortable because I don’t have anyone to come home to talk to. (Would you rather go back to a group home where you had other people to keep you company?) No. Sometimes I miss it, but not all the time (Respondent C-9, 1993).

Finally, the amount of social isolation that can exist is pointed out by Jerri:

I hardly go anywhere. It depends when I need something, then I would get out. Walk or ride my bike. Saturdays and Sundays, but it depends on if I need something. Monday, Tuesday, Thursday and Friday I am by myself. Then, Wednesday, I go to a group at [the agency] That meets every Wednesday. We went on trips. The two I liked best was when we to [name of location] and last year when we went to a state next door. (Respondent C-20, 1993).

(Do you have a social life?) Not really. I hardly get out. I thought this past week that I would have somebody come over, but that didn’t really work out. I don’t have a boyfriend. (Would you like a boyfriend?) Well, I thought......there was somebody I was talking to. And it didn’t work out. That really hurt my feelings. I was depressed. I come back here after work. I like being by myself. (Are you that satisfied with your social life?) No, I’m not (Respondent C-20, 1993).

Generally, full community integration for individuals with developmental disabilities still remains more of an ideal than a social reality for consumers. Several of the more notable reasons why consumers appear so disengaged from integration within the wider community are linked to structural features found in the agency. The agency, itself, neither actively goes about training consumers in the area of developing a network of
friends outside of agency residents, nor do they really provide effective strategies for overseeing this complex process. As pointed out, events which the agency does sponsor amount to only superficial efforts at integrating disabled and nondisabled persons. For example, the agency's premiere volunteer program utilizes college students who often receive college credit for their hours of service. One RPM discussed these volunteers and how the program may not be as effective as it could be:

Our [name of volunteer program] is ok, but it could use some work. It mostly gets me mad and my clients don't know what to make of it. First off, the programs are always the same. [What do you mean?] I mean we always do the same stuff...bowling, softball and the same kind of dances. I'm not knocking it though. It's good that my clients at least get out, and it gives staff a break too (Respondent S-01, 1993).

The problem with the program is that volunteers can be "iffy." You just can't count on them. I had some one year that were receiving credit for putting in so many hours. These guys all waited until the end of the semester and then all wanted to put in their hours. Well, I'll tell you. My clients were fed up with these volunteers by the end of it all. All they did was come over and watch t.v. with them. They didn't take them out and do things. Hell, my clients can do that any time they want. What they need is to do something different, something fun (Respondent S-01, 1993).

All these college kids wanted was to put in their hours and get their grades. I knew that some nights they brought their textbooks and just studied while my clients sat and watched t.v. That is not what volunteer programs are supposed to be about. My clients need to get more involved with different kinds of things. Not what they can do every night of the week (Respondent S-01, 1993).

Any volunteer program that emphasizes social integration is a step in the right direction. However, at times it appears that the program offers more problems than benefits. As with the RPM whose frustrations were presented above, it also has been my
experience that consumers often get frustrated with the volunteers. For example, many of these students don't show up when scheduled, and when they do, the students often prefer to remain at the residence rather than going out into the community. Even when suggestions are given to these volunteers, they tend to do what they want and there really is no one to whom complaints can be lodged. I feel that one of the major goals of any volunteer program should be to get consumers out into the community, not offer them more of what they get every day. Because of the politics and ownership involved, it is difficult to voice concerns about the structure and organizational goals of such programs, and, because of these and other safety and security concerns, it is impossible for staff to initiate other volunteer programs for consumers outside of the framework of the agency.

When some consumers attempt to go out on their own and integrate into society, they meet public resistance. For example, some of my own consumers traveled to one of the local malls to go shopping for dresses for a dance. Due to some of their physical characteristics, it was easy for clerks to recognize my consumers as developmentally disabled, i.e., downs syndrome, sight impaired, and so forth. They returned home without purchasing dresses, shoes, or anything else on their list. It was clear from their reactions that they were very upset. They explained that they had gone into one of the better department stores and found some items they were interested in, but they could not get the clerks' attention. They knew there were sales persons in the area, but every time they approached them, my consumers told me that the clerks walked away, or began helping other shoppers.
I returned to the store with my consumers where I witnessed this activity first-hand. The manner in which they were shunned was quite apparent and the message was clear - "we do not want you in here." I then went to another department, where I had a clerk page the manager, and then I explained the situation to her. The manager returned to the dress department with me, personally assisted my consumers, and then thanked us for our purchases. She then informed me that she would deal with her employees immediately. As we left the store she was speaking with the employees. Sadly, I felt that the employees would not take kindly to the dressing down, and that the incident might work to reaffirm in their own minds what they had initially felt - that the disabled were an inferior and troublesome lot.

Since dating is an important part of most consumers' lives, the final area or social environment I wanted to examine was that which concerned personal plans for their future. Specifically, I wanted to discover whether or not consumers felt they really could feel secure about their abilities to have a meaningful personal life which might include marriage and a family. Once again, I found that structural factors, especially the shortage of money, acted to impede consumers from achieving many of their desired goals. The following passages offer insight into these hopes and aspirations, along with directing attention toward their frustrations. Betty, explained her frustrations, even those brought on by the agency:

He wants to get married. I want to get married, but money is really tight. We can't afford it right now. He was married before, but I'm the one who's scared. I've never been married before. I think I can get used to it; we've been together for five years. His kids love me and I love his kids (Respondent C-10, 1993).
(Does the agency support you in your hopes for the future?) No! They don't. They let me do that on my own. They say they like my boyfriend but they really don't. (Do you think its racial?) Yea. I get flack from the agency. They say stuff to my boyfriend and say they like him, but when he turns his back, they talk down about him. They ask me if I'm ready for marriage and about if we have babies we'll get talked down, things like that. My drop-in advisor tells me that (Respondent C-10, 1993).

(Did they ever try to talk you into getting sterilized?) Yea. They used to a long time ago, but I told them no. They know I want a child. It's gonna come when it's supposed to come. (When you're married?) Well, maybe. I know it would be better to be married (Respondent C-10, 1993).

Another male respondent, Jim, stated:

The agency says now we got to start marriage funding. Start saving money for marriage. Then, hopefully, we can do it. (Who says these things?) The advisors. (What reasons do they give you for why it won't work out?) Finances. We have to take it out of our spending money (What would come out of your spending money?) Our money for the marriage (Respondent C-7, 1993).

We have plans for a big one, yea. We're gonna try. Mom told me it's expensive. Real expensive. When we get the money built up then. (Will your parents help out?) Nope. Not her folks or...we've already been told. They (the parents) think it's great. Her mom and dad thinks it's great. My mom and dad thinks its great. But both sides of the family don't have the money (Respondent C-7, 1993).

(How do deal with things since you're an interracial couple?) We get looks over at one mall, but not the other mall. My girlfriend just says, "Well, we don't go here no more if people laugh at us." (What is your future?) Future is marriage. My son getting to graduate and not ending up like me. I want something better for him (Respondent C-7, 1993).

The relationships and frustrations of any normal relationship are present in those conducted by consumers - the loneliness, the need for others, the pain, as one female respondent stated:
I don't have anyone to come home to. I used to date Bill. He's changed. We're just friends right now. But he's been thinking about coming back to me. He hasn't hit me once since we've been back together again. He's more like a lover. He doesn't get mad and hit me. He says he loves me and I'm the one he wants to be with. He says we have a lot in common. We like to eat the same things, do the same things. That's why he wants to keep me (Respondent C-9, 1993).

Another male discussed his personal frustrations and struggles with his girlfriend's father. Bob stated:

Yes, I bought a wedding set. Yea. We're planning on getting married during June of next year. That's on a Saturday. (What does everyone think about it?) Well, her dad doesn't really like the situation of me being with her. Because of our age difference. She's [her age] and I'm [his age]. Everybody but her dad in her family likes me, so far. Me and her dad don't socialize much (Respondent C-22, 1993).

When we put the invitations in the mail, we're going to say, "We aren't going to force you to come, aren't gonna pressure you to come." If he comes, that's fine. If he doesn't come, that's fine too. If he won't socialize with me, we can always figure out something else (Respondent C-22, 1993).

One respondent, who was married, reacted this way to questions about marriage:

The marriage seems to be going just fine. We've been married for two years now. We seem to have our problems, but we always seem to work things out. Right now its more or less on my end. A little bit of money problems. I only have a part-time job; it's only a couple of days a week. (So money is tight?) Yes, for both of us. My husband has gone from part-time to full-time, back down again to part-time (Respondent C-4, 1993).

His job is very "iffy." He's been at his job for two years now. I tell him to watch what he brings home. We don't have much room. Both of us are "keepers." We keep everything. He is a good husband and I'm still in love (Respondent C-4, 1993).

Thus, even in the most intimate parts of a consumer's life, the agency and its staff have a great amount of influence. Quite often, relationships between consumers is the
topic of conversation between staff and the consumers they serve. The reason for this is clear. Personal, intimate relationships are just as important to consumers as they are to members of the "normal" population. One big difference is that quite often consumers have a more difficult time sorting out their feelings and emotions. Since staff persons are often viewed as friends, they often act as a "sounding board" for their consumers. They often seek answers and guidance from staff, and, within that exchange, the power really lies with the staff. I know of situations in which consumer dating relationships caused staff a great deal of frustration, i.e., it was troublesome for the staff to deal with.

In one case that I know of, rather than working with the man and woman involved in a relationship that was having trouble, the staff person preferred to paint her consumer's boyfriend as someone who was not worthy of the woman. After a few days of sending out the message, the female consumer received it and opted to discontinue her relationship with the man. It was the end of the problem for the staff person and the beginning of a very lonely period for the consumer. One consumer who had a child reported that staff persons can become involved in the personal lives of their consumers.

For example, in discussing her own situation:

It [my social life] ain't great. The guy who used to live here with his mom, he comes here; but they [staff] don't like it. I like him and it's hard to let go. They keep asking me why I keep letting him in. Why I keep doing that and everything. And I tell them that its because I still care for him. (Respondent C-19, 1993).

I feel like telling them [staff] to mind their own business. They don't have to like him, or sleep with him, they don't even have to talk to him. They don't have to look at him. But I tried to tell them that way once, but they [staff] told me that he was not a good influence on my kid and they
brought up a whole bunch of stuff like that and they told me they would take my kid away from me (Respondent C-19, 1993).

They [staff] always say that they are going to take my kid away for this thing or that. They're always....[frustrated]...I told her [staff]....they always say that. I think they [staff] are trying to come up with something real stupid so they can take my kid away. I asked [name of staff person] why they always threaten me like that and she said it's because it always works. They [staff] threaten everybody [consumers with children] with their kids. The advisors threaten everybody by threatening to take their babies away (Respondent C-19, 1993)!

Quality of Life: A Mixed Message

My examination of quality of life issues was based on Goode's (1990) conceptual scheme that involves quality sets. These quality sets included the interaction between the consumers and their home environments, their work settings, and, finally, their communities. By interviewing consumers, rather than depending upon reports from staff, I was able to capture what I believe was a more factual representation of the interaction that takes place in these life spheres. In addition, my interviews demonstrated that consumers had the ability to understand many complex issues, and, perhaps more importantly, they demonstrated that they had been enculturated with values and had formed feelings, attitudes and opinions and which were expressed with thoughtfulness and clarity.

Coupling these data with those on normalization, some preliminary findings can be detailed. If the agency was to receive a report card for its role in normalizing its consumers, then I believe that it would receive a below average mark in two of the three areas examined. It would receive a passing mark for its efforts in developing housing programs, but below average marks for advocating for better jobs and full community
integration. Agency personnel may try to make the case that employment is not their concern, and, to a certain degree, they would be correct. However, the only way to ever improve the lot for consumers is to advocate for better jobs, pay, and benefits. In addition, consumers' best interests need to be looked out for by the agency. But, according to some management-level employees, this is not the case. This is especially true when it came to the agency's role as advocate and monitor of the sliding-fee scale payment plan in which consumers are required to take part, i.e., client participation. The agency must act as advocate to make sure that its consumers only pay what amounts to their fair share. However, from what I have learned, this is not always the case.

According to one management-level employee:

The agency really rips off its clients, and I feel confident in saying that they know what they're doing. I believe that decisions are made every week that hurt different clients by taking money from them. It's what some might call a "bookkeeping oversight" However, if I know about such things, then others most certainly do as well (Respondent M-7, 1993).

Whenever a client has a reduction in income, the county and DHS act to reduce his or her client participation amount. You know, the amount clients pay to the agency for their services. Well, since clients and most direct-care staff are not aware of these details, often the agency will not inform the staff or client that a reduction has taken place and they keep receiving the same amount of client participation, while, at the same time, they receive an increase share from the county (Respondent M-7, 1993).

In a sense, then, what is happening is the agency collects a certain percentage of its fees twice. Once from the county, who begins paying more, and again from the client, who continues to think he or she owes the old amount. It really is a horrible way to run a business and I think it stinks to rip off our own clients. You can't make waves on this, and as long as direct-care staff and clients remain in the dark, the agency will continue to collect double for its services (Respondent M-7, 1993).
I think the worst part of it all stems from the fact that whenever the decision is made that clients owe more, the agency jumps right on it and informs the direct-care staff that the client must pay, even if the client has to make payments to the agency in order to catch up. The reverse is not true. It's not handled as efficiently when the shoe is on the other foot (Respondent M-7, 1993).

Based on my own experiences with client participation, I can say that there are serious problems with the system. My own consumers have been victimized by bureaucratic red tape that works slowly to recognize changes in their income situation, resulting in overpayment for services. I do not recall one situation in which consumers have been reimbursed for "errors" made by the DHS, the County Board of Supervisors, or the agency. I believe that one of the reasons for why such seemingly illegal activities are permitted to develop and continue within the agency is related directly to the fact that there is no thorough system of checks and balances. In addition, as mentioned before, the agency and its leadership are not held accountable for such actions. If employees were to challenge the agency's management-level employees on this topic, they would most likely find themselves in trouble as doubt would be cast upon their loyalties and motivations.

The second area for which that the agency would not receive high marks is community integration. Again, the agency would probably claim that it has, in fact, done a commendable job in locating consumers within the community. I would find it difficult to offer a suitable argument for this position. The agency has done a good job at physically locating many of their consumers within the community. However, what the agency has failed miserably at is fully integrating them which must take into account the
social aspects of community integration. For the most part, accounts from consumers indicated that social isolation was a very serious concern for them. Many of the reasons why are structural and include such things as the lack of spendable cash, inadequate access to public and other, more flexible, transportation, insufficient training and opportunities to network and establish support systems outside of the agency, and the fact that the agency is structured in a fashion that seems to promote dependency rather than independence.

One of the last things I did during my interviews with consumers was to have them respond to a general question about their overall quality of life. Specifically, I asked consumers to rate their lives on a 10-point scale that ranged from "0" ("my quality of life is horrible") to "10" ("my quality of life is perfect"). From this line of inquiry, I concluded that 25% of the consumers rated their general quality of life high, (8-10 on the scale), 54.1% (4-7 on the scale) stated that their life was average (4-7 on the scale), while 20.9% responded that their quality of life was low (1-3 on the scale). Thus, from their own individualistic perspective, few consumers seemed to be impressed with their lives for one reason or another. It is interesting to note that even agency employees agreed that, generally speaking, life for their consumers was not that good. As part of Section One of the staff questionnaire, agency employees were asked: "At any given time, if I were forced to live the lifestyle of any one of my residents, I would feel satisfied about the quality of life." Only 8 out of 63 (12.7%) responded that they would be satisfied with their quality of life. Thirty-two (50.7%) stated that they were unsure how they would feel, and 23 (36.6%) stated that they would not be satisfied with living
the lifestyle of their residents. Surprising, these percentages almost correspond perfectly
with the responses presenting by the consumers, themselves, about their own lives.
CHAPTER SEVEN
DISCUSSION AND CONCLUSIONS

Gaining access to the inner-workings of an agency that operates residential care facilities for the mentally retarded presented me with a truly unique research opportunity. For while many researchers have attempted to disentangle details and educate members of the wider society about the world of the developmentally disabled, the "understanding gap" that separates the two groups remains wide. The reasons for why this situation continues are many, but the most compelling, in my opinion, is that persons with developmental disabilities continue to be devalued by society. In American culture, attitudes and norms appear to be at odds with one another as individuals with developmental disabilities are still considered as easy targets for discrimination. It is sad to know that many persons I have talked with over the years, even persons who I feel should know better, still express desires to see individuals with developmental disabilities in an institutionalized setting, i.e., to revisit the policies and practices of segregation. While some positive changes in attitudes have taken place in the wider society, people still experience a great deal of discomfort and unsureness when in the company of individuals who are physically or mentally challenged.

Positive changes have taken place within human service organizations during the past thirty years. It is obvious that individuals who reside outside of state-sponsored institutions have a much higher quality of life as they continue to work toward higher degrees of self-reliance and greater independence. However, this does not mean that
human service agencies are not without their share of problems. For example, while my data show that the agency had taken steps to assist individual consumers with community integration, many of the consumers I interviewed spoke of financial hardships and social isolation. At a more individual level within the agency, there appeared ample evidence to suggest that many potential obstacles laid in waiting for both staff and consumers. The most important of these obstacles included such things as negative attitudes held by staff, reports of situations involving abuse and excessive social control, some residential environments, and the lack of diverse employment opportunities. In addition, consumers were hard-pressed to become financially independent and suffered due to a lack of cooperation between the agency and other community and state agencies.

With respect to my original research goals, I feel they have been accomplished. I examined the feasibility of normalization, searched for and discovered various obstacles to the process, and, for the very first time, I was allowed to see how the consumers, themselves, came to construct their social reality as they discussed quality of life issues. My major conclusions are tied to these interests and the many research questions that developed as my study progressed and began to take on shape and order. Some of my findings, conclusions, and implications may be viewed as negative, even critical of the agency. Because of this, I feel that it is important to express at this time that I believe that the agency does deliver their consumers purposeful services which work toward increasing their consumers' education, skill levels, and their general quality of life.

However, as with any human service organization, there is always room for improvement and my findings and their implications direct attention to issues worthy of
rather than listing each of these findings, I have opted to select and highlight those I feel are the most important. My findings are presented below under the separate headings, as well as a detailed list of implications and recommendations.

**Normalization as a Philosophy and Delivery System Process**

1) Content analysis of official agency documentation, along with data originating from interviews with management-level employees demonstrated that the basic tenets of normalization were applied to its operations.

2) Most employees indicated that while they may define normalization somewhat differently, they all appeared to have a grasp of the concept's basic underpinnings. However, since diversity was found among the respondents, some definition and interpretation problems exist.

3) The agency's leadership has become too detached, uncaring, unwilling, or purposely deceptive with respect to acknowledging and reacting to the disparities that exist between two very different realities - one at the top of the agency and the other at the direct-care level. The most important reality, the one at the bottom, is the one that receives the least attention because consumers are not empowered by the agency.

4) The degree to which the agency actually works toward normalizing consumers is debatable. While the agency may appear to want to follow a normalizing service philosophy, it may also be just a cover for doing business as usual.
5) Many agency employees felt that their actions had little to do with normalizing their consumers and that the types of programming employed were inappropriate with expectations that were at time, "super-normal" in expectations. In other words, they were not allowed to make mistakes.

6) There is a need for a consolidated effort to make society realize that to devalue human beings, for whatever reason, is wrong. There is a need for both individuals and organizations to work together to "re-humanize" society in order to bring about positive change on the societal level.

**Internal Obstacles to the Process of Normalization**

1) Several structural-organizational impediments were detected. These included:

   a. different interpretations of social reality with respect to the success the agency was having with normalization;

   b. a somewhat detached leadership style found among management level employees, including directors;

   c. the fact that many layers of bureaucracy existed;

   d. there was a void when it came to the agency being held accountable for their programs; and

   e. faulty decision-making procedures led to serious frustrations among employees and appeared to not work in the best interest of the consumers.

2) In general, employees reported themselves as harboring negative attitudes toward their work and consumers in a few areas, including:

   a. wanting to push to accelerate consumers;
b. a strong dislike for administrative work;

c. the fact that they were not offered job security;

d. that almost half found that it was acceptable to become irritable toward consumers; and

e. that a clear majority held negative attitudes toward the sexuality of their consumers.

3) Significant numbers of agency employees reported knowing about staff who had gotten away with abusing consumers. In addition, most employees reported knowing about incidents that involved excessive, or surplus, social control.

4) Both management-level employees and direct-care staff reported that a serious rift existed between the two groups, and that this rift impacted negatively upon their consumers. A few of these reasons for this uneasiness include:

   a. defensive management styles;
   b. inequities in employee treatment;
   c. mis- and disinformation practices by management;
   d. lack of an effective open-door policy;
   e. staff bearing bad news are often punished; and
   f. problems stemming from group-think or collusive behavior.

5) Some of the features of a few residential environments were not conducive to the tenets of normalization, especially in traditional group home living.
External Obstacles to the Process of Normalization

Most management-level employees felt that external obstacles to the process of normalizing their consumers did not have much of an influence on the agency and its mission. However, I did find that some obstacles existed and appeared more influential than employees may have been willing to acknowledge, including:

1) the influence of funding sources and financial pressures to follow the demands of federal, state, and county agencies;

2) a general lack of sound inter-agency relations and cohesion due to inter-agency competition in residential services;

3) the threat of advocacy involvement in the agency reportedly acted to block advancement of consumers in the area of choice; and

4) a stubborn persistence from members of the wider society who still show signs of social intolerance for persons battling with disabilities.

Quality of Life Issues

Several quality of life issues surfaced during conversations with consumers. Some of the more important ones included:

1) a majority of consumers reported low to moderate QOL satisfaction;

2) consumers reported a general satisfaction with residential environments;

3) consumers' jobs were low in compensation and devalued;

4) consumers reported high levels of social isolation;

5) consumers reported significant amounts of excessive manipulation;

6) consumers were coerced into following directions;

7) consumers' financial situations limited real choices in their life;

8) consumers articulated very clearly their opinions; and
9) consumers had dreams and aspirations.

Implications and Recommendations

1. Create more personalized programs for consumers.
   * Educate consumers about options, choices, interests, and goals.
   * Interview each consumer in order to discover what is important to him or her.
   * Interview those who know consumers best to identify the types of support needs.
   * Identify and discuss barriers to goal achievement and decide upon strategies.
   * Observe and monitor program success and/or need for modifications.

2. Whenever possible, consumers should be allowed to choose where and with whom they live.
   * Evaluate consumer in order to know strengths and weaknesses.
   * Explain and suggest goal achievement strategies with consumer.
   * Ask for input from consumer about residential goals and preferences.
   * Agree upon a residential program with provisions for modification.

3. Whenever possible, assist consumers in their pursuit of leisure time activities.
   * Interview consumer to discover leisure time preferences.
   * Identify obstacles that might block consumer's goals.
   * Work to eliminate barriers and monitor.

4. The agency needs to seek ways to more fully integrate the consumer into his or her local community.
   * Establish if consumer has interests in taking part in community activities.
   * Identify any barriers to participation.
   * Provide support for consumer's wishes to become engaged in community.
   * Assist in educating wider community members; increase acceptance.

5. The agency needs to take a more pro-active role in providing consumers with a more wide-ranging system of networking, to include both disabled and non-disabled persons.
* Provide opportunities for consumers to establish contacts with others.
* The agency needs to work in ways that will facilitate this important activity.
* Contacts should stress building enduring friendships.

6. The agency needs to ensure that any consumer who wishes to expresses a desire for intimacy has the opportunity and any necessary support.

* The agency needs to provide training in regard to understanding emotions.
* The agency needs to provide training with respect to intimate relationships.
* Assistance may be required in using transportation and in making choices.

7. Consumers deserve to be free from all forms of abuse and excessive social control.

* The agency is required to inform staff and consumers on subject of abuse.
* The agency needs clear-cut procedures for reporting abuse.
* No retribution should befall those staff members who report abuse.

8. The agency must work toward winning their consumers more spendable income. As things stand now, poverty and disability are clearly linked.

* The agency must advocate that sliding-fee scales be reasonable.
* The agency should lobby on consumer's behalf in order for them to keep more of the income they earn from their work.
* The agency should prioritize training in fiscal tasks and responsibilities.

9. The agency should establish realistic educational and work background requirements for the positions offered, and remain consistent in seeking to fill these positions.

* In the past, the agency has hired people who did not meet official job description requirements, or it changed its own requirements to fit the individual preferred for the position.

10. The agency should incorporate more direct-care staff in specialized training which is currently reserved for management-level personnel.

* In the past, the agency has focused most special training sessions on management-level employees, including retreats and so forth. Direct-care staff could not only learn from specialized training sessions, but it would encourage some adopt a less alienated frame of mind.
11. The agency needs to provide evaluation feedback to staff on a regular basis.

   * The agency has not always ensured that supervisory staff have fulfilled the requirement for annual reviews of staff performance. Often the only time staff hear about performance is when something bad has taken place.

12. The agency should construct a system for ongoing evaluation in success for achieving desired outcomes in all facets of its operation.

   * The agency recognizes that this is a major weakness at the present time. Steps should be taken to ensure a reliable and valid evaluation process is established and employed.

13. The agency needs to ensure its mission statement includes clear-cut vision of its purpose and intent with respect to normalizing the consumers it serves.

   * At present, the mission statement does not include many specifics for staff. However, at the time this report was prepared, the agency was making an attempt to enlighten staff with respect to long-range planning and mission statement goals.

14. The agency needs to reduce the layers of bureaucracy. This would help those at the direct-care level feel less alienation and the cost-benefit could be applied to areas that have a positive impact on consumers.

   * Bureaucracies have a tendency to grow because leaders have a tendency to take part in what is referred to as "kingdom building." Often this results in isolation of staff and added paperwork due to duplication, even triplication, of administrative requirements.

   * Often leaders become so far removed from the day to day operations at the direct-care level that subordinates may feel that they cannot, or should not share information that runs contrary to the leaders' beliefs.

15. Ensure that all agency employees understand the concept of normalization and what it means to the agency with respect to the services they provide.
* While most staff appeared to have a general understanding about what normalization means, other responses indicated that many did not put into practice the philosophy’s principles.

16. Supervisory staff need to ensure that direct-care staff are aware of their responsibilities to normalize consumers and that they carry out the directives contained in approved programming.

* Most supervisory staff spend most of their work hours in the headquarters and away from the homes they monitor. Seldom do supervisors visit their homes at "odd" hours in order to achieve a better understanding of consumer and staff interaction, frustrations, and successes.

* Lack of direct contact may lead direct-care staff to the assumption that supervisors do not really care about the day-to-day operations in the home, and, in return, offer supervisors little respect.

17. Training needs to stress the definitions of abuse and excessive social control. Staff need to be aware of the types of abuse that exists and that the agency will not tolerate it.

* The data show that a lot of abuse and excessive social control goes on within the agency.

* Staff need to be made aware of the many types of abuse and how to avoid becoming engaged in such behavior.

* Abuse must be reported, but my impression is that little of it really is for two reasons. First, the staff may not understand just what abuse is, and second, they have a general understanding that in the target agency, the messenger of any bad news is normally the one who ends up in trouble. Perception or otherwise, the agency’s leadership needs to take steps to change this.

18. Leadership of agency needs to set example for others in management by giving more than lip service to the notion that direct-care staff are important to the agency.
At present, direct-care staff feel alienated from themselves, their work, and the agency.

Leaders must work to bridge the chasm that appears to exist between direct-care staff and management-level personnel. No matter how one may wish to deny its presence, the data are clear on how direct-care and some management employees feel.

19. Open lines of communication need to exist without the threat of retribution. Leaders need to make sure that all staff feel comfortable bringing up areas of concern.

As already mentioned, staff at all levels report that the message given out by the agency's leaders is one of "don't bring me any bad news."

The idea that the agency's directors have an open door policy is not perceived by staff as true, at any level.

20. The agency leadership needs to refresh themselves with respect to leadership traits and practice them.

Agency leaders should rely less on coercive leadership styles as most studies indicate that this method of leading is the least effective and the one most likely to alienate workers.

Agency leaders should attend workshops and seminars on effective leadership styles and practices.

Making Sense of It All

It is clear that the above listed preliminary findings are wide-sweeping and many of them overlap as they share specific elements of concern. In an attempt to move beyond the point of merely repeating information already presented in previous sections, I prefer to discuss these findings, implications, and recommendations in terms of a few larger questions that beg to be asked. Thus, I have formulated a few critical questions within
which many of these findings can be couched and deliberated. These questions include the following:

With respect to normalization:

* Is there a point at which the agency's goal of normalization becomes merely an ideological cover for just doing business as before?

With respect to obstacles:

* In what ways does the agency work hard to keep consumers in a "retarded," and, therefore, a dependent role while at the same time presenting the appearance of normalizing them?

With respect to quality of life issues:

* To what degree has the agency empowered consumers with meaningful choices in their lives?

* Is there a need to reconceptualize the idea of normalization, substituting in its place a more appropriate, guiding light that asks the other members of society to accept those persons who are physically and developmentally challenged on their own terms?

New Institutions - Same Ol' Business

After reviewing the data on normalization I find it difficult to discern the actual degree to which the agency is committed to truly implementing the principles of normalization. On one level, the agency certainly presents an appearance that strongly suggests that it does adhere to them. For example, there are ample passages in official documentation that demonstrate a commitment to normalizing delivery services for consumers. In addition, many of the management-level employees recognize normalization as the "driving force" which officially guides many of the decisions the agency makes about its services and consumers. Lastly, who can really argue against
the notion that many individuals with developmental disabilities are better off today than they were a few decades ago? While funding does remain a serious problem for the residential agency, most of its consumers and their families appear to be well-served and, most importantly, they are presented with more options today in regards to education, training, and residential settings than at any other time in history.

However, I also discovered that another side of the agency exists which presents a very different image. Specifically, I believe that the agency provides only "lip service" to the idea of normalizing its consumers, and, based on many of the data, certainly does not always grant consumers premier priority in many of its dealings. For example, while the agency offered a comprehensive collection of personal and human rights to their consumers, the degree to which each of these rights was actually granted remained vague. In addition, several accounts from employees demonstrated how consumers' rights were often temporarily suspended and used as a tools for manipulating consumers. Further, the agency did not have a single policy penned that somehow protected and guaranteed, even discussed, its consumers' rights to engage in a fulfilling sexual life. To me, this was a very telling indicator of a more general pattern that showed the agency as an organization that lacked foresight and sufficient sincerity when it came to implementing some of the most basic tenets of normalization. Lastly, consumers were to have the right to humane and dignified treatment and services, but, according to both employee and consumer accounts, consumers were routinely victimized by staff who abuse their positions by repeatedly engaging in techniques of surplus social control.
Another area in which the agency took pride, to which its directors eagerly attest, was that of consumer participation in agency decision-making processes. However, I detected that consumers often were systematically denied this role. In most settings, there was a general lack of effort when it came to educating consumers about their role in the decision-making process. The one exception noted concerned their role during interdisciplinary staffings, state-mandated meetings which required the presence of the consumer. Consumer staffings take place at different times during the year and it is during these one-hour meetings that many important things transpire, including: a) a variety of consumer programming is planned for one year, b) consumers are evaluated with respect to work and residential performance, c) family members are allowed to ask questions and voice concerns, d) consumers are provided with encouragement, praise, and, at time, corrective suggestions, and e) consumers are asked to provide input about their programming needs and desires. While consumers are asked about things during these meetings, it is also very clear from taking part in many of them that it is a stressful time for them. In many ways, consumers just play along with the course of the meeting, knowing what their role is and playing along with suggestions. If consumer requests appear reasonable and there are no financial conflicts, they are incorporated. However, for the most part, this variety of decision-making bears no influence upon the agency's operations. According to several management-level employees, agency decision-making has always been and will continue to rest with the management-level employees and the agency's directorship which remain several bureaucratic layers removed from the consumers.
Data collected in the course of this study also drew attention to other areas in which the image of a caring and concerned agency were challenged. These included: a) consumer treatment lacked respect and dignity, and there were reports of breaches in confidentiality, b) advocacy for consumers by non-agency parties was viewed as troublesome; what one management-level employee referred to as the "biggest threat" to the agency, c) the lack of cooperation between sister-service organizations, and d) the fact that consumers themselves are not asked about their quality of life. This last feature touches upon the fact that several of the agency's directors acknowledged that they had no instrument for self-evaluation and accountability. The import of this should not escape the reader since it, once again, focuses attention on the fact that consumers are not only assigned a secondary status by members of the wider society, but, sadly, also within an agency whose most preferred image is one in which it is shown to skirmish against such social indifference and discrimination. This finding is of great importance as it touches upon so many of my study's implications and recommendations. I would be hard-pressed to provide a more sobering example of what I mean by agency posturing and the "lip service" it reportedly directs at consumers and the wider public alike.

The opportunities and probability for change within the agency is greatly decreased by both group-think and collusive behavior. Those nearest the top in the agency have a tendency to think alike, to table issues and concerns, and to express any resemblance of "individuality" along management lines. Additionally, a majority of agency employees reported that they felt they could not, even should not, approach the agency's leaders in truth and honesty. During conversations with various employees, I often heard tales
about how the agency's directors preferred to "kill the messenger" of bad news rather than following a more appropriate course of action which might remedy the situation. The message sent to employees is simply to keep quiet and just do your jobs. By default, they have been coerced into taking part in behavior that perpetuates a general lack of accountability. With no one demanding accountability from the agency's leaders, they are free to continue to operate the agency in ways that may be counterproductive to the agency's mission goals. One management-level employee commented about the agency's leadership in this fashion,

[name of director] has openly stated that she is open and accessible and I know very few people who have done that. She does not intend to present an intimidating presence. However, it's clear to see that she is power-tripping. She is defensive and challenging. I know a few people who have challenged her and stated their piece, and I think that they are paying for it right now. I know of one employee who decided to quit because she got tired of the bullshit. She left in good standing, but was not hired back because [name of director] knew she was likely to speak her mind. She left in good standing, was excellent with the consumers, but she made the mistake of speaking openly about her feelings and concerns. End of story (Respondent M-1, 1993).

This is especially true when it comes to reporting abuse. Recalling that several agency employees discussed the fact that one of the highest ranking employees failed to follow-up on at least two very serious situations involving the sexual abuse of agency consumers offered a rather pathetic example of how potentially damaging this style of management can become, i.e., damage control management which places agency image above consumer safety and well-being. Such decisions not only threaten the security of consumers, but they reportedly led to more sexual abuse of at least one consumer involved. Once undertaken by an agency's leadership, it always seems that lies beget lies
and these types of activities often lead to irreversible harm to the agency's prestige and position within the community when and if the facts are ever disclosed. Decisions to cover-up or attempts at misinformation always run a high risk of failure. These and other issues and findings point to the fact that the agency's true nature with respect to normalization remains very nebulous.

It is interesting to note that among human service organizations like the target agency in this study, particular points of confusion like the discussion just offered are not rare phenomena. One intriguing reason for this was offered by Flynn and Nitsch (1980) who pointed out,

....among human service agencies in North America and other parts of the world which have demonstrated an "adoption-in-theory" of normalization, only a few have made any significant progress toward an "adoption-in-practice" (pg. 364).

With respect to the point made by Flynn and Nitsch, I believe my data suggests one of two things: a) that the agency has not arrived at a point where it has put into practice much of what it professes (i.e., it still operates from an adoption-in-theory stance), or b) that if the agency has seriously attempted to adopt normalization in practice, it has done so by constructing and maintaining a delivery structure that appears micro-managed, disjointed, and depressingly full of contradictions, i.e., the agency has performed at far below par standards. There may be a few "legitimate" reasons for why the agency follows more of an adoption-in-theory approach. For example, the agency may claim that it is because funding continues to be restricted and many programs that might otherwise benefit its consumers are not affordable. In addition, the agency's leaders may
speak about their responsibilities to ensure consumer safety and security are given priority and this may play a role in restricting consumer freedoms and rights. I tend to believe that other issues and attitudes offer a more accurate explanation.

First, as much as the agency claims to have moved away from former service paradigms in which consumers were very tightly controlled, such a major transition or shift in philosophies might be difficult. That is, the philosophy of normalization might be offering the agency's leaders and other employees a serious challenge when it comes to adopting and implementing a more radical, albeit contemporary, service delivery perspective. However, with external pressures to conform to normalization, the agency may feel strongly compelled to at least present an illusion of change, or, at best, a modicum of measured change to business as usual. McCord (1982) asserts that when human service agencies function in that regard they often opt to operationalize goals in highly visible, but innocuous manners. That is, agency leaders may attempt to present illusions of adoption to normalization by taking part in public discussions of the issue, or by transcribing their ideological principles into official documentation. However, at the agency's core, nothing of substance really changes. This practice is what Goffman (1959) described as "cleaning up the front region" in order to present a favorable impression of the agency to the public.

One of the most dangerous consequences of presenting only the illusion of change is that direct-care staff often come to view themselves as custodians of consumers rather than as key teachers and mentors. I believe that this has happened within the target agency. The unfortunate results of this is that agency staff: a) do not always view
normalization and its principles seriously, b) do not follow through with assigned programming, c) view their consumers as less deserving of dignity and respect, and d) that no matter how much the agency and its employees would like to believe they have the best interests of their consumers at heart, it just is not so. I believe that the data I collected support this findings. Sadly, when an agency's leaders make the decision, consciously or otherwise, to not demonstrate in both word and deed the very principles of normalization they wish to infuse in their employees, then their employees will recognize the agency's official goals as little more than phony rhetoric. Having seen through this actual or perceived "do as I say and not as I do" strategy, agency employees will be hard-pressed to demonstrate little more than token fidelity to practicing the concept's tenets. The agency is in need of an objective method for measuring its own success. Without it, I believe that the agency is doomed to devour itself, not unlike like a cancer gnawing away as it consumes it's host from the inside out.

In Search of Success at Normalization

It is important to be alert to what history has to say to us, for we do not want to see history repeat itself. Unquestionably, we must resist a re-emergence of the pejorative attitudes and dehumanizing treatment that prevailed toward the end of the 1800s. Most disturbing is the fact that some features of the field today are not so different from those of many years ago (Patton et al., pg 31, 1990).

Prior to beginning this study, I was a strong advocate for and totally convinced that normalization was the key to successfully integrating those society labels as developmentally disabled. It appeared that the process would allow many disabled to be assimilated into the wider community where they would be accepted and given their fair
share of human dignity and respect by members of the wider society. Presently, I am still a believer in the idea of normalizing consumers. However, I believe that as implemented within the agency focused on in this study, it has failed to pass muster. The reason for its failure is not because the concept is lacking in worthiness. Frankly, I believe normalization is the best conceptual scheme human service agencies have to offer consumers. Rather, its shortcomings stem from a human service-wide failure to recognize that in order to normalize consumers, the process must take into account its multi-level nature and identify and work toward level-specific goals. To recall for a moment the ideas first discussed by Wolfensberger (1980), normalization has a conceptual schema that takes into account three distinct levels of operationalization: the individual, the organizational, and the societal. In order for normalization to flourish in a complete sense for consumers, then successful action and programming must be taken at all three levels.

I believe that my data, especially those collected from consumers, indicate a massive failure of the agency to recognize and address the important issues and influences associated with societal-level entities. This negligence accounts, in part, for why the agency has only partially fulfilled its obligations to their consumers. Some critics of my findings may question such a statement by noting that the agency has been very successful at placing many consumers in independent residential settings within their communities, and they would have a valid point. As stated, I do believe that the agency has done an admirable job at physically integrating its consumers into the community. However, while it has physically integrated them into the wider community, it has failed
to do all that it can to ensure that they are socially integrated as well. Thus, it is imperative that along with developing serious programming, training, and education for both consumers and staff, the agency must assume a more pro-active position with respect to re-educating the public and reshaping society’s structural arrangements, negative cultural values, and attitudes which act to block the normalization of consumers. A brief examination of the system demonstrates this shortcoming and its results.

When most consumers begin to receive services from the agency, they have few skills. Their training programs are structured in such a way as to teach a variety of independent living skills, as well as promote and teach widely accepted standards of social conduct. The main idea is to provide consumers with enough personal skills and social understanding and maturity that they will be able to function on their own, and as far as their individual desires and abilities will carry them. The results of these years of training pay off for consumers as they advance to residential settings in which less structure is required. Ultimately, if and when evaluations show that the consumers have proven themselves, they are placed in apartment settings within their own communities with minimal services and support. When this happens, the agency can look at these persons and feel good about itself. It has, after all, proven itself somewhat effective at the individual and organizational levels in the normalization scheme. However, upon closer examination, agency success may neither be as clear-cut, nor as complete as it first thought.

Even though highly independent consumers have proven themselves within an institutional structure and begin living on their own, they are far from socially integrated
within their communities. Sadly, some of the consumers expressed concern that they had never been so lonely or isolated as when they began to live on their own. While some of the reasons for this are situational (e.g., lack of transportation, meager financial means, etc.), another factor impacting upon their situation is the a general failure of the agency to accomplish two things: a) to assist consumers in developing networking skills which would allow them to begin and sustain friendships and acquaintances in both disabled and nondisabled populations, and b) to assist members of the wider society to accept and value consumers as individuals, hopefully resulting in more tolerance and less prejudice and discrimination, and more opportunities to crossover socially constructed boundaries.

If the agency does not attempt to meet these needs, consumers will tend to remain dependent upon the agency, its staff, and the other disabled consumers it serves for their social identification and support. To not develop programming to intervene in these areas will ensure that the agency remains only partially successful in fully integrating its consumers into the wider society. To fail in this endeavor will help ensure that consumers remain dependent upon, rather than independent of, the agency. I believe that human service organizations need to respond to this challenge by re-examining, reformulating, and even replacing if necessary normalization as their preferred delivery system philosophy. I believe that rather than continuing with the facade of normalizing individuals with developmentally disabilities, human service workers should be about the business of helping to create and promoting a social environment in which individuals with developmentally disabilities are looked upon as worthy of respect and, therefore, should be trained and assisted in order that they might fulfill meaningful social roles.
At present, it appears as if the agency has developed and maintained only one service option. This option appears more aimed at ensuring the preservation of the agency as a business, more so than exercising options that serve consumers in a fashion that might see them become totally independent of the agency's system for support. For example, when management-level employees were asked how many consumers had actually "graduated" from the services the agency offered, they remarked that while no consumer had actually left from the service, a few had voluntarily opted to leave the agency and strike out on their own. According to one management-level employee, it was clear that this "consumer dependency" was causing some concern among funding agencies. In particular, the employee was concerned that the agency would be required to develop its first thorough strategy for evaluating itself in a fashion that would offer interested parties objective, trustworthy accountability:

We have a problem with our clients remaining dependent upon us. When funding agencies look at us, they see that we have served the same clients for many, many years. We don't appear in their eyes to have a door which clients can open and move on beyond the agency. They don't appear to be out there in the community on their own. In the future, I am not sure that this will be the case. I honestly believe that we are going to have to create some form of measure by which we can show concerned agencies that we have moved people out of the agency and into the community as independently functioning persons. This will open the door at the other end for the many clients and their families who have been waiting for services (Respondent M-12, 1993).

The agency appears satisfied to work toward producing in their consumers some form of counterfeit normality that leads to a form of simulated independence. By this I mean as the agency goes about the business of telling and showing consumers what is normal, staff members instruct them in behavior expectations found in the wider, so-
called normal society. Staff teach them how they should think and act in normalizing terms and situations. However, when they do achieve some degree of normality in their lives and they are packed off to an apartment setting. There the social world that confronts them is often cold, hostile, and judgmental, and whose members prefer to label these new members as deviant, first and foremost. The result is another form of cruel segregation. Thus, while the consumer may have worked hard to change themselves, members belonging to the society into which he or she moves often stubbornly resists accepting them.

What is needed is a residential service system that recognizes that its services and training under the guise of normalization must reflect the concept's true nature and take into account its different levels of abstraction. In essence, the agency must see that its training and consumer preparation strategies reach beyond the individual and organizational level demands found within the residential service agency, by setting its sights on tasks found within the wider community setting. Both environments, the residential service agency and the community, have problems that need to be addressed. Within the agency, staff must have a cohesive understanding of what normalization is and how it is translated into residential settings and training. Staff at all levels need to work in harmony with one another toward the goal of assisting consumers in their attempts at increasing their social and independent living skills; to take them as far as individual capabilities and personal talents permit. At the same time, the agency and other human service organizations and social institutions need to be more responsible when it comes to
working for positive attitude change among the members of the normal community population.

If members of the wider community are not willing to accept individuals with developmental disabilities on their own terms, then toward what ends do residential human service agencies and their workers strive? Agencies cannot just say that their responsibilities end when consumers enter the community. What is the point of "normalizing" consumers when at the end of their training they are placed into a society that neither recognizes their accomplishments, nor wants to consider them normalized and equal heirs to human dignity and respect?

A Plan for the Future

The agency examined in my study, like so many other human service agencies, is successful in attaining its primary mission goal of assisting many individuals with developmental disabilities in achieving their goal of greater independence. During the past seven years, I have witnessed first-hand and, on several occasions, the personal joy, satisfaction, and triumph that eventuates when individuals achieve their short- and long-range aspirations. In the human service field, the principles of the normalization philosophy simply direct workers as they go about the business of assisting individuals who work toward greater levels of self-reliance. While service delivery systems based on these principles may appear far from problem-free, they do appear to offer positive results. However, agencies need to do more than take care of business within the confines of their own organizations. There is a need for them to become more involved
in the creation and maintenance of social conditions which might act to enhance the probability of success once consumers leave their residential support system.

I agree with Wolfensberger (1992) who states that both individuals and organizations need to work toward breaking down the barriers that lead to the social devaluation of people; in the present case, the devaluation of an entire group of person labeled developmentally disabled. Sociology clearly shows that who gets devalued in any particular culture is, to a large extent, determined by what a society values or defines as bad, ugly, and unworthy. In America and many western cultures, what is valued most is productivity based on competence, wit, intelligence, and self-reliance. Because these things are so highly valued, those found wanting in any of these traits are often victims of some of the most damning, long-term discrimination possible in western culture (Clinard and Meier, 1985). This is why, according to Scheerenberger (1983; 1986), so many individuals with developmental disabilities have been devalued socially, economically, and politically for so many years. Many persons in modern American society believe that people who cannot fend for themselves "deserve" to have their life socially constructed by those who are more capable and equipped to "know better."

What needs to be done is to insist in changing how members of the wider society think of persons who are challenged with disabilities. Rather than focusing on personal differences that stem from a person's genetic code, an unfortunate accident, or some environment factor, members of the wider society need to be re-educated in order to first see the individual and then, if really necessary, take into account differences. One thing is for certain, such a shift in social attitude will never take place unless interested persons
and the power of organizations are brought together in an effort to re-educate and reshape public attitudes and opinions. One approach is offered by Wolfensberger (1992) whose strategy includes a two-prong technique, including both image-enhancement and competency-enhancement strategies directed at consumers who receive services from human service organizations. Both of these strategies are in place in the agency to one degree or another at the present time. For example, image-enhancement was noted in the following areas:

1) the agency's housing is situated in normalizing neighborhoods;
2) the agency employs competent direct-care staff;
3) the agency reinforces the need for and value of work;
4) the agency insists on the use of normalized terminology;
5) the agency takes pride in the appearance of its consumers and staff; and
6) the agency is beginning to seek new funding sources for expansion of services.

Competency-enhancement is accomplished in the agency in the following ways:

1) training is on-going, wide-ranging, and geared to greater levels of competencies;
2) training is individualized, focusing and developing strengths;
3) social competencies are stressed - stress on instrumental competencies, and;
4) programming is relevant and meaningful.

While the agency demonstrated that it delivered services that were relevant to the competency needs of its consumers, it needs to do more with respect to the potency and sincerity with which it develops and delivers its services. The agency needs to develop an effective, intensely long-range means through which funding for new and old programming can be sustained. There needs to be more attention paid to activities such as grant writing, private and public solicitations for fiscal assistance, and other innovative
means for supporting individual consumers, e.g., volunteer efforts, "adopt a program" efforts, and so forth.

While the agency has set the groundwork for doing a respectable job with both image- and competency-enhancement, it cannot afford to become static or satisfied with its performance. For the agency's consumers to be successful in their goals, the gap that exists between consumer and members of the wider community must be narrowed and eventually closed. In order for this to happen, the agency must begin to listen to its consumers, understand their needs, and then respond by developing and implementing programs that not only assist their consumers, but take into account the need to "re-humanize" members of the wider society. Hopefully, at some point in time, the public will recognize that to treat individuals with developmental disabilities as less than human is to error most grievously. To assist in this endeavor, human service agencies need to develop comfortable strategies in which to show members of the wider community that consumers should be appreciated and provided with valued social status and roles. When this happens, I believe we can honestly begin a healing process that is long overdue in all of us.
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APPENDIX A:

AGENCY EMPLOYEE SELF-ADMINISTERED QUESTIONNAIRE
Your decision to take part in my study is appreciated. This questionnaire covers many aspects of your work as a service provider so please be careful to respond to the questions and statements in each section.

SECTION ONE
NORMALIZATION

Provide a written response to the following questions (please print):

1. What does normalization of individuals with developmental disabilities mean to you?

2. In what ways are your residents' efforts to become normalized blocked? That is, do you see any obstacles to the normalization process? If so, what are they? Provide a few examples.
SECTION TWO
OPINIONS ABOUT WORK

Indicate your response to the following statements by circling the one best choice. Responses range from 1 = "Almost Never" to 7 = "Almost Always".

1. I feel that I contribute to getting things done at work.

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7

2. I feel that my concerns are listened to by my immediate supervisor.

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7

3. I feel that my job is challenging.

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7

4. I feel that I am needed at work.

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7

5. My job makes me feel "burned out."

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7

6. My residents are fully accepted by members of the wider community whenever we travel into the community.

ALMOST NEVER
ALMOST ALWAYS
1 2 3 4 5 6 7
7. Individual Program Plans really help my residents achieve a higher level of independence.

ALMOST NEVER   ALMOST ALWAYS
1  2  3  4  5  6  7

8. At any given time, if I were forced to live the lifestyle of any one of my residents, I would feel satisfied about the quality of my life.

ALMOST NEVER   ALMOST ALWAYS
1  2  3  4  5  6  7

SECTION THREE
ATTITUDES

Indicate your response to the following statements by circling the one best response. Use the following scale to indicate your answer:

circle "A" if you strongly agree
circle "a" if you mildly agree
circle "d" if you mildly disagree
circle "D" if you strongly disagree

A a d D 1. It's natural for staff members to "blow their tops" when residents get on their nerves.

A a d D 2. A good staff member should shelter residents from life's difficulties, even small ones.

A a d D 3. Staff should not criticize residents in public.

A a d D 4. The sooner a resident is weaned from emotional ties to the staff, the better he/she will be.

A a d D 5. Staff should not allow residents to be exposed to situations which may be difficult.

A a d D 6. Staff members should encourage residents to be independent.
7. Laughing at residents' jokes and telling jokes to residents make things go more smoothly.

8. Community residences should take steps to see that staff are relieved of unnecessary cleaning and housekeeping.

9. It would be a good thing if the staff could be relieved of most of the activities involving direct physical care of sick or dependent residents.

10. Most staff feel somewhat insecure in their work.

11. Residents should be kept away from all jobs which might be discouraging.

12. Changing soiled linens and bathing sick or severely disabled residents are pretty depressing jobs at times.

13. If there is one thing that staff members dislike, it's working with residents that need total physical care.

14. On bad days, I sometimes wonder why I ever took a job in this agency.

15. Residents can get on any staff's nerves after being with them all day.

16. Staff must earn the respect of residents.

17. Residents should be encouraged to tell staff when they feel rules are unreasonable.

18. The staff should always "go to bat" for their agency, regardless of whether or not they agree with its policy and practices.

19. There are a few staff members who can be sweet and even-tempered with residents all day without letting them get on their nerves.

20. There is no reason staff should have their way all the time; any more than residents should have their way all the time.
21. Working in a community residence is not very rewarding much of the time.

22. Staff should adjust to the resident rather than expect the resident to adjust to them.

23. A resident will benefit later on if the staff are strict now.

24. When you do things together, residents feel close to you and can talk more easily.

25. Residents should be allowed to disagree with staff if they feel their own ideas are better.

26. A resident has a right to a point of view and should be allowed to express it.

27. A resident should learn to rely on staff for solving most problems.

28. Staff members are completely satisfied with the job their agency is doing.

29. Working in a community residence sometimes presents more headaches than it's worth.

30. Residents are too often asked to do all the compromising and adjusting, and that is not fair.

31. People who work in a community residence often would rather be doing some other kind of job.

32. Staff who are interested in hearing about residents' activities outside the home help them progress faster.

33. Managing our residents is a nerve-wracking job.

34. The staff should always be pushing residents to develop as soon as possible.

35. Residential agencies like this one are often unjustly criticized.

36. Most staff members feel that paperwork is pure drudgery.
37. There are so many things to be done, that it seems like a waste of time for the staff to have to do all the bathing and physical care of sick or dependent residents.

38. Most residents are dealt with too leniently when they cause problems.

39. Residents should be pushed to develop as soon as possible.

40. Most staff members frequently wish that they had taken up some other line of work which pays more.

41. Staff are required to do too much housekeeping in their residences.

42. If the staff would have fun with their residents, the residents would be more apt to take their advice.

43. Staff members should treat residents as their equals.

44. When things go wrong, the staff member is the one who usually gets the blame.

45. Most residents should be disciplined more than they are now.

46. Staff members often are worried about doing something which will cause them to lose their jobs.

47. In working at a community residence, one never knows of what he or she may be accused.

48. Residents are actually happier when they are made to "toe the line" at all times.

49. A resident's idea should be seriously considered in making house decisions.

50. Often, staff members are reprimanded for reasons that are not important and for things that were not their fault.

51. The sooner a resident is weaned from emotional ties to the staff, the better off he/she will be.
52. Residents are happier and better behaved when staff members show an interest in their affairs.

53. Of all the jobs in a community residence, cleaning up, and keeping the records straight are the most boring.

54. Entirely too much record keeping is required of the staff.

55. Strict discipline develops a fine strong character.

56. When residents are in trouble, they should know they won't be punished for talking about it with the staff.

57. When I hear others comment unfavorably about our agency, it makes me angry.

58. Staff often feel that they can't stand their particular group of residents a moment longer.

59. Most staff prefer to perform jobs other than giving direct physical care to residents.

60. Residents should learn to come to staff for advice, even if the decision to be made is very minor.

SECTION FOUR
GENERAL TOPICS

Indicate your response to the following statements by circling the one best response. Use the following scale to indicate your answer:

circle "A" if you strongly agree
circle "a" if you mildly agree
circle "d" if you mildly disagree
circle "D" if you strongly disagree

1. House rules are necessary when it comes to running a residential program, even if they conflict at times with a resident's rights.

2. I believe that my residents should be considered my equals.
3. I believe that the opportunities for community integration (outside contact) my residents currently experience is sufficient.

4. I believe that my residents get to do the things they really want to when it comes to their leisure time activities.

5. I believe that if I had a resident who was really "difficult to work with" I would try to get the resident transferred to what I consider a more appropriate setting.

6. I often feel that I must "do battle" with my residents in order to get them to conform to some of the demands of their programs.

7. I believe that my residents are given ample opportunities to have direct input concerning decisions made about them.

8. I believe that in reality, I really do control many aspects of my residents' lives.

9. Many times, prescribed procedures of Individual Program Plans (IPPs) are not followed.

10. I believe that staff are justified in arranging things in a manner which is convenient for them (the staff) rather than making sure residents do things in the most "normalizing" manner.

11. I believe that because of the time and energy demands placed on me, it is near impossible to adequately normalize all my residents.

12. I believe that there are times when I am justified in manipulating different aspects of my residents lives.

13. I believe that residents are often treated as "something less than human" by staff members.
SECTION FIVE
OPINIONS OF SEXUAL BEHAVIOR

Indicate your response to the following statements by circling the one best response. Use the following scale to indicate your answer:

- circle "A" if you strongly agree
- circle "a" if you mildly agree
- circle "d" if you mildly disagree
- circle "D" if you strongly disagree

1. Persons with developmental disabilities who have been caught having sexual intercourse should be kept apart.

2. If observed, residential staff should stop residents from masturbating.

3. Every person, disabled or nondisabled, has the right to have children.

4. Adolescents who are developmentally disabled need occasions to meet with the opposite sex privately.

5. Homosexuality between persons who are developmentally disabled who enjoy it should be permitted.

6. Persons who are developmentally disabled should be able to get contraceptives when they want them.

7. Individuals with developmental disabilities have the right to make their own decisions about their sexual lives.

8. Persons who are developmentally disabled have stronger than average sex drives.

9. I would be worried that a homosexual resident might "corrupt" other residents.

10. All residents should have some place to go for private behaviors.
11. On average, women who are developmentally disabled are more promiscuous.
12. Most persons who are developmentally disabled will seek sexual pleasure of some kind.
13. Persons who cannot support themselves should not get married.
14. Residential facilities should keep male and female residents as separate as possible.
15. Persons with developmental disabilities have less need for sex the nondisabled persons.
16. There should be residential facilities for married persons with developmental disabilities.
17. Residential staff should stop homosexual behavior.
18. The state should pay for contraceptives for sexually active residents.
19. Residents have the right to have sexual intercourse if they want to engage in it.
20. Most residents I know would be unable to make responsible decisions about sex.
21. Residents who become pregnant more than once should be involuntarily sterilized.
22. Residents who become pregnant should receive counselling about abortion.
23. Residents who live in a traditional group home setting who desire to engage in sexual intercourse should be allowed the time and privacy required.
24. All persons classified as lower functioning in developmental disability should be sterilized when they are young.
25. All individuals with developmental disabilities experience sexual drives and urges.
SECTION SIX
NEED FOR CHANGE

What could/should your agency do to improve itself with respect to serving the needs of the consumers. That is, in your opinion, what, if anything, needs "fixing" and how should it be fixed (continue response on back of last page if necessary):

What could/should your agency do, if anything, to improve the quality of life your residents experience (continue response on back of last page if necessary):

SECTION SEVEN
ABUSIVE BEHAVIOR

Several studies have shown that individuals with developmental disabilities are often the victims of physical, emotional, and sexual abuse, as well as different forms of "excessive social control." Without asking you to provide specific details, respond to the following statements which focus on such behavior. The word "staff" in the following statements can mean either you and/or other staff members (circle the one best response):

Yes No 1. I know of situations in which staff have "gotten away with" physically abusing residents.

Yes No 2. I know of situations in which staff have "gotten away with" emotionally abusing residents.

Yes No 3. I know of situations in which staff have "gotten away with" sexually abusing residents.

Yes No 4. I know that residents are routinely manipulated by staff in a variety of ways.

Yes No 5. I know of situations in which other residents have "gotten away with" abusing other residents under my care.

Yes No 6. I know of situations in which residents' family members have "gotten away with" abusing them.
7. I know of situations when personal choice was taken away from residents. That is, I know of situations when staff made decisions for residents when residents themselves should have been part of the decision-making process.

8. I know of situations when staff opened mail addressed to residents without the residents' knowledge.

9. I know of situations in which staff have "gotten away with" yelling at residents.

10. I know of situations in which staff have "gotten away with" purposely punishing residents in some fashion that went beyond any IPP guideline.

11. I know of situations in which staff have "bullied" residents.

12. I know of abusive situations which should have been reported, but for some reason(s) were not.

13. I know of situations in which residents were "set up for failure" by staff.

14. I know of staff who can't stand for residents to "get away with things."

15. Considering for a moment physical, emotional, and sexual abuse, how many abusive situations are you aware of involving staff and residents within the last 12 months?

_________ (provide specific number.....0, 1, 4, 6, 12, etc.)

16. Considering the use of what you might call "excessive social control" (e.g., manipulation of environments for specific outcomes, rights not granted, holding back information from residents, phrasing things certain ways, and so on), how many of these situations are you aware of involving staff and residents within the last 12 months?

_________ (provide specific number.....0, 1, 4, 6, 12, etc.)

17. Several studies report that staff members routinely manipulate situations in order to get their residents to respond in certain, often preferred, ways. You may have personally been involved in such practices, or you may be aware of situations in which other staff have manipulated their residents. In the space provided below, list a few of the ways in which staff routinely manipulate their residents (if necessary, use the back of the last
RESIDENTIAL INFORMATION

Please respond to the following information.

1. Number of residents you serve: _________

2. Type of facility you presently work in (circle one):
   
   a. traditional group home
   b. waiver home/HCBW
   c. scattered-site program/apartment complex
   d. other (explain: ___________________________)
   e. I work at the agency's headquarters

3. Position held (circle one):
   
   a. residential program manager
   b. residential program assistant
   c. residential program aide
   d. program director/associate director/director

Other comments which you feel are relative to my dissertation topic can be placed on the back of this page. Once again, thank you for taking part in my study on normalizing individuals with developmental disabilities.

Please seal your completed questionnaire in the stamped, pre-addressed envelope and place it in the mail.
APPENDIX B:

SPATIAL ANALYSIS SURVEY
SPATIAL ANALYSIS WORKSHEET

I. Characteristics of Residence

Type of Facility:

a. traditional group home
b. waiver home
c. apartment complex
d. scattered site apartment
e. other: 

Resident to Staff Ratio:

Number of residents: 
Number of staff: 

Average Level of Functioning of Residents: Low Moderate High

II. Normalization of Physical Environment (Indicate if Present or Not Present):

1. Inside homelike appearance  P   NP
2. Cheerful, warm interior  P   NP
3. Individually decorated bedroom  P   NP
4. Homelike appliances/fixtures  P   NP
5. Comfortable non-standardized furnishings  P   NP
6. Age-appropriate environment  P   NP
7. Normal risk-taking fixtures  P   NP
8. Outside lawn appearance  P   NP
9. Private storage for personal items  P   NP
10. Flexibility of interior design  P   NP
11. Design conducive to privacy  P   NP

III. Community and Neighborhood

1. Location of residence: remote walking distance to town in town

2. Approximate miles to town's center from residence: 

3. Forms of transportation available to residents:
   a. MET
   b. taxi
   c. van
   d. car
   e. other: ____________________________

4. Distance to nearest public transportation: ____________________________

IV. Which of the following services are located within a reasonable distance from the residence:

- corner store
- shopping mall
- supermarket
- clothing store
- library
- public park
- school
- medical services
- restaurant
- movie theater
- bank
- laundry/dry cleaners
- athletic field
- fast-food place
- church
- social/rec. club
- post office
- bowling
- mental health center

V. Neighborhood Characteristics

Look at the structures immediately surrounding the residence and check all that apply:

- vacant or agricultural land
- trailers
- apartment house
- multiple family house
- public park
- detached single family house
- apartment in partly commercial building
- school/government building
- other:

__________________________
VI. Residence Fit

How does the residence blend with the surrounding residential neighborhood:
1. extremely different
2. somewhat different
3. typical structure
4. residence is not located in residential neighborhood

VII. Other Areas of Interest
1. Does house have "house rules"?
2. If yes, are they posted?
3. If yes, do all residents have a copy of them?
4. If yes, how are residents made aware of them?

If yes, request to know if there are rules that govern:

5. Bedtime hour Yes No
6. Telephone usage Yes No
7. Laundry time Yes No
8. Emotional outburst Yes No
9. Contact between sexes Yes No
10. Group outings Yes No
11. Meal hours Yes No
12. Television watching Yes No
13. Recreation hours  Yes  No
14. Time-out procedures  Yes  No
15. Visitations  Yes  No
16. Ingestion of food/drink (times and locations)  Yes  No
17. Smoking restrictions  Yes  No
18. Use of household appliances  Yes  No

Additional Comments:
APPENDIX C:
CONSUMER QUALITY OF LIFE INTERVIEW SCHEDULE
NORMALIZATION/QUALITY OF LIFE STUDY
INFORMED CONSENT FORM

(READ THE FOLLOWING STATEMENT TO THE RESPONDENT. PRIOR TO BEGINNING THE FORMAL QUESTIONING, THE RESPONDENT MUST SIGN THIS FORM.)

"I want to ask you some questions about how you usually feel about your life. I will ask you things about how you like where you live, where you work, your school days, your social life, and about the town you live in. You don't have to answer any question that you don't want to, and we'll stop anytime you want to. Will you please explain what I have just read to you? Do you understand what I have explained?"

(IF THE RESPONDENT HAS ANY QUESTIONS, ANSWER THEM BEFORE GOING ON.)

"I will not tell anyone about the things we talk about. These things are considered 'secret' and will stay between us. I will not tell anyone what you say. I will not tell members of your family, your friends, or your supervisor. Your name will not appear on any report I write. Will you please explain what I have just read to you? Do you understand what I have explained?"

(IF THE RESPONDENT HAS ANY QUESTIONS, ANSWER THEM BEFORE GOING ON.)

"There are no right or wrong answers. I only want to know how you feel about things. Will you please explain what I have just read to you? Do you have any other questions before we begin the interview?"

(IF THE RESPONDENT HAS ANY QUESTIONS, ANSWER THEM BEFORE GOING ON.)

"I would like to ask you to sign this form. Your signature means that I have read this paper to you and that you understand what I have said. It also means that I have permission to go ahead with this interview."

_________________________________________  ____________
Respondent's Signature                      Date

By placing your initials here (_____), you have indicated that I have permission to tape record this interview session.
DATE: ________ LOCATION OF INTERVIEW: __________________________

1. Person's Name: ____________________________________________

2. Age: ________

3. Marital Status

   Single, Never Married: ________
   Married: _______________
   Divorced: _____________
   Widow/Widower: ________

4. Education

   Last School Attended: _________________________________________
   Graduated: Yes No

5. Approximate Annual Income: _________________________________

6. Current Living Environment

   Group Home: __________
   Waiver Home: __________
   Apartment Complex: ________
   Independent Apartment: ________
   HCBW: ________

7. Number of Others Living With Respondent

   Males: __________
   Females: __________

8. Does Respondent Share Bedroom Area: Yes No
9. Employment

No Employment: __________
Goodwill: __________
Competitive Employment: __________ (Where: ________________)
Day Program: __________ (Where: ________________)
Other: __________ (Explain: ________________)
How long at current job: ________

HOME SETTING

1. How long have you lived here?
   History of past residential experience.

2. What are some of the best things about this home?

3. What are a few of the things you don’t like about this home?

4. Would you like to move from here if it was possible?
   If yes, to where?

5. How often do your friends come over for a visit?
   What do you do with friends when they visit?

6. Can you have a pet here?
   If no, would you like to have one?

7. What are some of the rules you must follow here?

8. What do you like to cook?

9. Where do you go shopping? How often? Transportation?

10. Who does your housekeeping?
IF RESPONDENT HAS ROOMMATE(S)

11. Do you enjoy your roommate? What are the problems?
12. Would you prefer to live alone?

13. What do you do to keep yourself busy at home?
14. How often do you get bored at home?
15. What do you do to feel safe and secure in your home?
16. What kinds of training do you take part in at home?
17. Do you like the neighborhood around here?
18. Do you know your neighbors?
   How often do you speak to them?
19. In what ways does living here make you feel independent?
20. What do you like about the staff who help you?
21. What do you dislike about the staff who help you?

LEISURE TIME

1. How many days a week to you spend at home?
2. What do you like to do when you have free time?
   How often do you do these things?
3. What things do you do with your free time?
4. What things are the most fun?
5. What would you like to do in your free time that you can't do right now?

6. How often do you go out with friends?

7. How often do you get together with your family?

8. Can you do anything you want in your free time?

9. What house rules stop you from doing what you would like to do with your free time?

10. Do you have enough friends?

11. Do you wish you had more friends?

12. Do you have any problems with transportation?

13. Can you freely go out into the community?

14. How do you get around in the community?

WORK SETTING

1. What kind of work do you do?

2. How many days a week do you work?

3. How many hours a day do you work?

4. What do you like about the place you work at now?

5. If you could do the kind of work you wanted, what would you choose?

6. What are some of the bad things about your work?

7. What would you change at work if you were given the power?

8. How important is work to you?

9. Do you feel your education prepared you for life?
Ways it did -

Ways it didn't -

10. What kind of pay and benefits do you receive for working?
11. Does your job provide you with enough money to buy the things you want?
12. How closely are you supervised at work?
13. What kind of rules do you have at work?
14. Do you think the rules at work are fair?
15. What rules should be changed?
16. What do you do with your paycheck?
17. How often do you pay your bills?
18. How do you budget your money?
19. How do you get your spending money?

COMMUNITY SETTING

1. How often do you get out into the community?
2. What do you do when you go into the community?
3. Do you belong to any clubs or organizations (church, etc.)?
4. How many times a week do you talk with your neighbors?
5. Do you have friends come over for visits?
6. How often do you attend recreational activities in your community?
7. Do you have many friends who are nondisabled? How often do you do things with them?

8. Do you have a girlfriend/boyfriend?

9. How often do you date?

10. Do you have to rely on others in some way if you want to go out on a date? What obstacles exist? (Transportation, etc.)

11. Do you have any curfew rules?

12. Do you have enough money to spend on free time activities?

13. What is a typical date like for you?

14. Do you ever.....
   - go to parties:
   - go to church:
   - go to restaurants:
   - go to bars:
   - go to movies:
   - go shopping:
   - go out for exercise:
   - go to clubs or social groups:
   - go to sporting events:
   - listen to radio:
   - watch television:
   - play cards/games:
- do crafts:
- go for walks:
- visit with friends/family:
- go bowling:
- go dancing:
- other: