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Individuals with Mental Retardation and the Transition to Independent Living

Andrea M. Fadel

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**INDIVIDUALS WITH MENTAL RETARDATION
AND THE TRANSITION
TO INDEPENDENT LIVING**

by

Andrea M. Fadel

An Abstract

**of a thesis in partial fulfillment of the
requirements for the degree of Master of Science
in the School of Health Sciences and Human Performance at
Ithaca College**

September 2000

Thesis Advisor: Catherine Y. Gordon, Ed. D., F.A.O.T.A.

ABSTRACT

Mentally retarded individuals face many challenges when transitioning into the community. Among these are difficulties in transitional living skills. Currently there is very little research on community programming for individuals with mental retardation. In this study a survey questionnaire assessed the transitional practices of occupational therapy personnel in New York State and discovered what elements were most commonly included among transitional living skills. Respondents also rated these elements as important or unimportant.

Overall, occupational therapy personnel were found to work with younger children using a developmental approach, and worked minimally in the transitioning process. Those therapists who work in transitioning, often used the traditional roles of evaluation and individual treatment when working with consumers. The skills that they taught were primarily those that related more to basic ADLs such as feeding or eating, dressing, and oral hygiene, even though they recognized the need for training in more complex IADLs particularly emergency response, medication routine, and health maintenance. Analysis of rural and urban centers did not indicate meaningful differences.

Findings from this study will be useful when identifying effective treatment approaches for mentally retarded individuals who are transitioning into the community. They also reflect a real need for more occupational therapists to provide programming leading to the acquisition of transitional living skills for individuals with mental retardation or developmental disabilities.

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**A Thesis Presented to the Faculty
Of the School of Health Sciences and Human Performance
Ithaca College**

**In Partial fulfillment of the
Requirements for the Degree
Master of Science**

**by
Andrea M. Fadel
September 2000**

Ithaca College
School of Health Sciences and Human Performance
Ithaca, New York

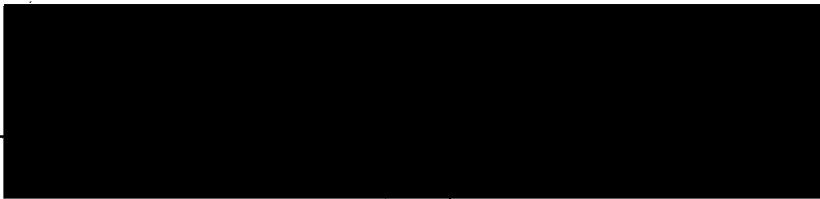
CERTIFICATE OF APPROVAL

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Master of Science in the Department of Occupational Therapy, School of Health Sciences
and Human Performance at Ithaca College has been approved.**

Thesis Advisor: _____



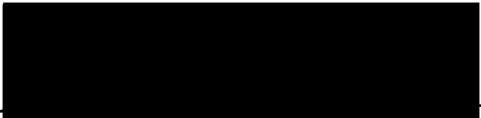
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To my aunt Kathleen, thank you for all the help and information that was useful in the completion of this project.

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Dedication

This work is dedicated to my family, whose love, support and encouragement have made this all possible.

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INTRODUCTION

Mental Retardation

Mental Retardation (MR) affects approximately three percent of the world's population (Berkow, 1995), and is the most common form of developmental disability. According to the United States Department of Health and Human Services, mental retardation is a cause of major activity limitations for those afflicted (United States Department of Health and Human Services, 1996). In New York State in 1993, approximately 5.7 persons per 1,000 aged six to seventeen were diagnosed as having mental retardation. In addition, 6.2 people per 1,000 ages eighteen to sixty-four were similarly diagnosed (Huang & Rubin, 1997).

Mental retardation is described as sub average intellectual ability combined with difficulties in learning and social adaptation (Huang & Rubin, 1997). It is usually present at birth or early infancy, and the condition is largely unchanging throughout life (Edgerton, 1979). If impairment occurs anywhere from zero to eighteen years, it may be defined as mental retardation. In most cases of mental retardation, the cause is unknown. Common known causes include:

- Excessive maternal consumption of alcohol or the use of drugs
- Radiation therapy
- Poor nutrition
- Viral infections such as the German measles (rubella)
- Chromosomal abnormalities such as Down syndrome
- Difficulty during birth (prematurity, head injury, low oxygen levels)

- Heredity disorders such as phenylketonuria (Berkow, 1995).

Mental Retardation is classified into four levels, based primarily upon the individual's intelligence quotient (IQ). An IQ range of 52-68 is described as mild mental retardation. At this level, the individual is able to develop social and communication skills. He or she may show slight impairment of motor coordination. Academic skills may reach the sixth grade level, and these individuals can usually achieve enough social and vocational skills in order to be self-supporting (Edgerton, 1979).

The second level of mental retardation is the moderate level; with an IQ between 36-51. Moderate mentally retarded people can learn to talk or communicate, however social awareness may be poor. There are slight impairments in motor coordination, and this is especially noticeable during self-help activities. People with moderate mental retardation can usually achieve up to a second grade academic level, and can eventually learn to do unskilled or semiskilled work traditionally in sheltered conditions (Berkow, 1995).

The third level of retardation is the individual with severe mental retardation. The IQ range for these individuals is generally 20-35. At this level, an individual can be expected to say a few words and learn simple self-help skills that are habitual, such as tooth brushing or hand washing. He or she may participate in some higher-level skills with supervision. Muscle coordination is often poor, and supervision is usually necessary (Berkow, 1995).

The fourth and most severe form of mental retardation describes the profoundly mentally retarded individual. This label refers to someone who has an

IQ of nineteen or below. Often these individuals will have accompanying neuromuscular, orthopedic, or language difficulties. Self-care is very limited, and custodial care is usually required. The incidence of MR within the four levels tends to decrease as the severity of the mental retardation increases. A large percentage of the mentally retarded population falls within the mild to moderate category (Berkow, 1995).

The physical, emotional, and intellectual abilities of mentally retarded individuals are influenced by the kind of care and education they receive (Edgerton, 1979). Historically, programs for MR have focused on maximizing academic function and on provision of custodial care. The programs may or may not have included vocational training and independent living training. Over the last thirty years, however, increased focus has been placed on maximizing the ability of the individual with mental retardation to function at his or her highest level within the community. There has, therefore, been a growing movement to assist individuals with MR in making the transition from sheltered living, work, and school environments to independent community living and working (Decker & Thornton, 1995). This brings with it a change in the programming needs for these individuals, particularly in young adulthood.

Transitioning is defined by Brollier (1994), as "the process by which a student is prepared to leave the school setting and enter into employment and community living" (Brollier et al., 1994, p. 346). The necessity for transitioning for individuals with disabilities has been legally mandated in the school system for persons between the ages of fourteen and twenty-one. Provisions for occupational

therapy and other related services are also mandated in transitioning. Transitioning requires the involvement of the family, the student, and a variety of professionals who work with the student. These individuals must all collaborate to determine transitional objectives in the domains of domestic, community, recreational, and vocational living (Brollier et. al., 1994). Interventions should then focus on functional daily life and readiness skills.

Functional skills that are necessary for these individuals to transition with ease into independent living may include vocational adjustment, money management, daily living skills, and social and interpersonal communication (Bruininks & Lakin, 1985). These students must be encouraged to perform these functional skills in multiple environments, including ones that are integrated with 'normal' individuals. It is important that students be given opportunities to practice functional skills while they are in school in an effort to foster the transitioning process.

Transitional programming that is offered within the school system is one way for individuals with disabilities to acquire community living skills. According to New York State Regulations of the Commissioner (1999), transitional services are "a coordinated set of activities for a student with a disability, designed within an outcome-oriented process, that promotes movement from school to post-school activities including, but not limited to, post-secondary education, vocational training, integrated competitive employment (including supported employment), continuing and adult education, adult services, independent living, or community participation" (Weller, et. al., 1999, p. 4). It involves coordinating activities that

are client-centered, and are based on the individual's specific needs, preferences, and interests. Overall, transitional programming and transitional services both work to enable young people with disabilities to become productive and independent members within the mainstream of society (DeFur & Taymans, 1995).

Individuals with mild, moderate, and severe levels of mental retardation are capable of both learning and living with some level of independence. Therefore, it is important to consider transitional issues while the individual is in school so that he or she can become better equipped to deal with the transition into the community following high school. Some of the issues that should be addressed include whether the individual will obtain employment and be self-sufficient, the level of support that will be necessary in employment or community living, and whether the person will be able get around independently within the community.

These are only a few of the areas to be considered when transition planning. This is especially true for students with MR while they are in secondary school. Over the course of four years, the student must prepare to leave the school system and student role, and enter the larger adult community. It is important to understand what areas need to be considered in order for an individual to function within the larger society. The following areas should be included when developing a transitional program that will facilitate acquisition of overall independent living skills: occupational and vocational education; availability of job opportunities; wishes for furthering educational level after secondary school; availability of transportation to and from work, school, home, doctor's appointments, and leisure activities; financial resources available to the consumer;

the individual's legal rights; and the availability of advocacy groups should also be taken into consideration (Weller et. al., 1999, p11).

According to Smith, (1998), an estimated forty five-thousand people with disabilities have their housing needs met by state and voluntary programs.

Wherever they live, many people with mental retardation need some assistance in their daily lives. It may range from maximal assistance with activities of daily living such as dressing or going to the toilet, or minimal assistance with complex instrumental activities of daily living such as money and time management.

Therefore, when planning for housing for someone with disabilities, it is necessary to include a support services plan. This support service plan should take into account the individual and his or her needs, as well as the resources that are available (Smith, 1998).

Occupational Therapist's Role

It is the responsibility of the occupational therapy profession, along with other members of the team who work in the transitioning of consumers, to determine the course to take and the treatment to provide to ensure that clients receive effective treatment during the transitioning process. It is also important to assure that they can experience success in community living. Independent living and maximizing function are concepts that have long been valued by occupational therapists. This is especially true when working with the mentally and physically handicapped who require training in specific skills to achieve independence in their daily roles of work, leisure, and maintenance activities. This is exemplified in the American Occupational Therapy Association's definition of occupational therapy

(OT). Occupational therapy is "the therapeutic use of self-care, work, and play activities to increase independent function, enhance development, and prevent disability. It may include adaptation of [a] task or [the] environment to achieve maximum independence and to enhance the quality of life" (AOTA, Representative Assembly Minutes, 1986, p. 482).

Occupational therapists are trained to assess the environment and to adapt it when necessary. Another core concept of occupational therapy is also to examine the balance between work, play, rest, and leisure in a person's life. For these reasons, it is important that occupational therapists work to help individuals gain transitional skills so they can perform daily activities within the community. To provide OT services effectively, further research is needed to determine what key elements make up a successful transitional program for individuals with mental retardation.

With the introduction of civil rights and educational legislation in the seventies and eighties, the role of occupational therapists in the school setting has changed (Huang & Rubin, 1997). There is now more emphasis placed on an education that is appropriate to the student's abilities and goals, and which prepares them for adult living. There is also an increased emphasis placed on the development of skills that will allow the individual to transition with increased ease from a traditional school setting to an independent life in the community. It has been assumed that these programs work, but there is little research that determines if or why these programs are successful, and what elements indicate that transitional living programs have quality and success. Interpretation of these

programs may lead to identification of specific elements of the program that should be used to increase success of the individual in the community.

Discovering what key elements make up a successful living program is important in the field of occupational therapy. It would help to ensure that clients receive the best, as well as the most cost-effective, treatment. Occupational therapy treatment is an expensive service, and clients deserve to know about the best treatment options. Successful and happy living is also important to clients who want to live independently.

Statement of the Problem

It is often difficult for parents of children with mental retardation to look into and plan for the future. Unlike 'normal' individuals who do much of their own planning, persons with mental retardation must rely primarily on their parents, schools, and support systems for this same planning (Blodgett, 1971). The transition process involves a great deal of decision making on the part of the family, the individual who will be transitioning, and the members of the team who work with the consumer. An informed choice about the best way to transition the individual can only be made when there is adequate knowledge and understanding of both the options and the consequences of the choice (Weller et. al., 1999).

There are currently programs in place that work specifically toward integrating and transitioning disabled individuals into the community. However, little has been done thus far to examine the role that occupational therapy can or does play when working with transitional living programs or the effectiveness of these transitional living programs. With the increasing costs of services, it is important that the occupational therapy profession look into the best possible interventions for its clients. In occupational therapy, further research is needed to determine the key elements of a successful transitional living program for individuals with mental retardation and the role of occupational therapists in this area.

Purpose of the Study

The purpose of this study was to determine the role that occupational therapists play in the process of transitioning individuals having MR or DD into community living. The study also examined the theoretical models that are primarily used when working with individuals who are transitioning. Therapists were evaluated on the perceptions that they have about the services they provide, and the perceived importance of these services when working with the mentally retarded population. A comparison was done to see if urban and rural based OT's placed the same importance on issues of transitioning. All of this was done through the use of a mail survey that sampled 150 occupational therapists in New York State who are members of AOTA. Through this study, we sought to learn what occupational performance skills occupational therapists believe contribute to the success of transitional living programs.

Limitations and Delimitations of the Study

This study will focus on only one aspect of transitional programming, independent living.

Only 150 occupational therapists working with individuals having developmental disabilities or mental retardation were surveyed. It is expected that some of these individuals may not work in the transitioning of their consumers.

All occupational therapists recruited for this study were members of the American Occupational Therapy Association's Developmental Disability Special Interest Section. This may not be representative of all occupational therapists in this practice area.

This study will only look at programming for the mentally retarded and developmentally disabled population, and it therefore cannot be generalized to all populations.

The non-standardized survey was designed specifically for this study and has not been tested for reliability and validity. It was pilot tested by classmates and professional faculty members for initial content validity only.

Assumptions of the Study

The first assumption is that the subject group is reasonably representative of occupational therapists serving mentally retarded individuals.

The second assumption is that occupational therapy personnel involved in the transitioning process will fill out the surveys accurately and honestly.

The third assumption is that the survey accurately measures what it is supposed to measure.

Definition of Terms

Societal Trends

Deinstitutionalization: "The shunning or avoidance of traditional institutional settings for the care of the mentally disabled, and the concurrent expansion of community-based facilities for the care of these individuals" (Bruininks et. al., 1981).

Institutionalization: According to Wolfensberger (1972), it is "a deindividualizing residence in which persons are congregated in numbers distinctly larger than might be found in a large family; in which they are highly regimented; in which the physical and social environment aims at the lowest common denominator; in which all or most of the transactions of daily life are carried on under the roof, on one campus, or in a largely segregated fashion" (Bruininks & Lakin, 1985, p. 4).

Integration: A movement where severely handicapped individuals attend school with other non-handicapped youth. They often share the same physical facilities, and may be in a few classes or groups together for periods of social interaction and educational and social activities (Bruininks & Lakin, 1985).

Mainstreaming: An educational movement where handicapped students are educated within regular classes with 'normal' students instead of in segregated schools or classrooms.

Housing Options

Family Care: A living situation in which an individual lives with either family or friends. It is funded by state, local, or private money.

Group Homes: Neighborhood homes for up to ten individuals, that are staffed twenty-four hours a day. Individuals living in a group home may require greater than two hour, but less than twenty-four hour supervision, and services can range from providing total assistance to moderate supervision.

Home Modifications: Adaptations made to the home that are necessary to maintain or increase one's ability to live at home with independence.

Independent Living Centers: A living facility where staff is on site twenty-four hours, however, services are used only as needed.

Independent Living Services: Services provided to help people with disabilities develop more control over their lives and to live more independently in their own communities.

Living Independently: Living in an apartment or a house on one's own, and without any support services.

Supported Living/ Live-in help: Living within a home or an apartment where a live-in aide is available in the home around the clock to perform instrumental activities of daily living (IADL's).

Transitional Living/Supported Apartments: Apartment living for one to three people who have reached a high level of independence. Counseling intervention may be necessary for the individuals living within the apartment, however, no on-site support staff is required.

Employment Options

Enclaves/ Mobile Work Crews: A group of five to eight individuals working together with a staff supervisor. The goal is for individuals to develop work skills

in a structured setting and move on to more individualized work settings (Weller et. al., 1999).

Independent Employment: Finding and maintaining a job without any outside assistance or support. Advocacy and assistive technology may be provided as needed (Weller et. al., 1999).

Sheltered Employment: Training or work in a workshop with other persons with disabilities. There is subcontracted work with local industry, state, and federal government. Wages are sub-minimum wage (Pierson, 2000).

Supported Employment: A program for individuals who need on-going support to remain in community based employment. Wages are at or above minimum wage (Pierson, 2000).

Transitional Employment: "The placement and time-limited training for a specific job. The length of time during which support and training are provided ranges from very limited to approximately 250 hours of job coaching" (Weller et. al., 1999, p. 28).

Occupational Therapy Terminology

Activities of Daily Living (ADL): Activities such as, but not limited to, mobility, eating, toileting, dressing, grooming, and other activities related to personal needs.

Instrumental Activities of Daily Living (IADL): Tasks beyond basic self-care that include tasks such as cooking, cleaning, shopping, using the phone, doing laundry, money management, banking, driving or the use of public transportation, housekeeping, and other activities involved in living independently (Hopkins & Smith, 1993).

Functional Limitations: The behaviors or conditions of a person that impair the ability to provide for personal needs.

Transition Terminology

Individualized Education Plan (IEP): A written statement of the educational program that has been designed to meet the individual's unique needs. It specifies the programs, placement, and services that the individual will receive. It also includes a description of the individual's educational status, goals, and objectives.

Least Restrictive Environment (LRE): Part of Public Law 101-476, the Individuals with Disabilities Education Act (IDEA), that states the child has the right to be placed in an appropriate setting and the right to be educated, when possible and where possible in a program as close to home as possible. According to Pataki, it is the provision of services to meet the individual's needs in a manner which least interferes with the individual's normal day-to-day activities (Smith, 1998).

Person Centered Planning: An approach and a method to foster new ways of thinking when planning with a person who has a disability. The process begins with the individual and focuses on developing personal relationships, positive roles in the community, and skills for self-empowerment.

Traditional Planning: The process in which professionals and parents make decisions for the student without student input. Usually the student is absent or present but may not be included in the discussion or decision-making.

Transitional Services: A coordinated set of activities for a student, designed within an outcome oriented process, that promotes movement from school to post-school

activities, including post-secondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living or community participation.

VESID: "The Office of Vocational and Educational Services for Individuals with Disabilities-is a part of the New York State Education Department. It helps people with disabilities that are eligible for vocational rehabilitation services to find and keep suitable employment. Provides vocational rehabilitation services to eligible individuals to prepare them for employment consistent with their strengths, abilities, and interests" (Smith, 1999, p. 1).

Types of Disabilities

Developmental Disabilities (DD): A broad categorization of individuals who include, but are not limited to those individuals with the following disorders: mental retardation (MR), learning disabilities (LD), Attention deficit/hyperactivity disorder (ADD/ADHD), autism/pervasive developmental delay (PDD), and/or dual diagnosis of psychopathology or behavior disorders associated with MR (Kurtz et. al., 1996).

Developmental Delay: The non-specific term for children under five years of age with developmental skills below the level expected for age. It is reserved primarily for preschool children with developmental variance that is at least twenty-five to fifty percent below the mean (Kurtz et. al., 1996).

Mental Retardation (MR): Below normal intellectual functioning that has its cause or onset during the developmental period. It results in impaired learning, social adjustment, and maturation. It is categorized by severity: mild, having an IQ

between 50-70; moderate, having an IQ between 35-55; and severe, having an IQ less than 35 (Toward Independence, 1999).

Normal: Any individual without a mental or physical handicap having an intelligence quotient above 70.

Research Questions

- What theoretical models are primarily used when working with individuals having mental retardation or developmental disabilities?
 - Are different theories used based on the age of the individual being served?

- Who are the primary team members that work with individuals having mental retardation or developmental disabilities?

- To what extent are occupational therapists involved in transition planning for individuals with mental retardation or developmental disabilities?

- What is the occupational therapist's role in transition planning and programming?

- What services are provided when working on transitioning of consumers, and what services are perceived as being needed?

- Are there any differences in how urban-based therapists view the availability of employment, transportation, housing, and self-advocacy groups in comparison to rural-based therapists?

REVIEW OF THE LITERATURE

Introduction

"Since the late 1960s, under the influence of deinstitutionalization, tens of thousands of mentally retarded people have been moved from state institutions to smaller residential facilities, to their natural families, to independent living, and to other types of community-based placement" (Bruinincks et al., 1981, p. xi). The United States made a formal commitment to the goal of independent living for people with severe disabilities in the late 1960's and 1970's. This is tied to the civil rights movement and the trend toward deinstitutionalization. This commitment was marked by the passage of the Vocational Education Act in 1963, and the Amendments to the Rehabilitation Act in 1978. These very important steps have already brought about enormous changes to the lives of disabled citizens and to the field of rehabilitation. Whether this progress continues to occur is dependent on several factors, including the extent of financial commitment from the government, the cooperation of consumers and service providers, and community awareness (Crewe, 1979).

Mental Retardation and Independent Living

Historically, persons with mental retardation have experienced discrimination in employment and housing based on their physical and/or mental deficits. Their access to community-based employment and housing has been limited. Rehabilitation legislation currently exists that prohibits discrimination based on disabilities. There is now a legal obligation for schools, businesses, and

housing sites to provide equal access for individuals with mental retardation (Mayerson, 1998).

According to the American Association on Mental Deficiency (AAMD), there are three key elements necessary to understand mental retardation in relation to independent living. These include capabilities, the environment, and the level of functioning (Huang & Rubin, 1997). Capabilities are the attributes that enable a person to function in society such as vocational skills, cognitive skills, and social skills. The environment is the setting in which an individual lives, learns, works, and interacts. It includes such things as job availability and accessibility, the social atmosphere, access to transportation, and availability of housing. The level of functioning is the highest level that the individual will be able to achieve, and it takes into consideration the degree of need for supports, and whether the need is intermittent, limited, extensive, or pervasive (Huang & Rubin, 1997). Function can be influenced as much by the nature of the person's environment as it is by the person's capabilities, and the existence of limitations in adaptive skills occurs within the context of the community environment (Huang & Rubin, 1997). The goal of independent living is full participation and integration of a person with a disability into society (Bowen, 1996).

Historical Factors in Independent Living

To understand the independent living movement, it is first imperative to realize what events led to this drive for independent living. Initially, Public Law 88-210 helped individuals without developmental delays smoothly transition into the community and independent living by mandating the use of vocational

training in high school in addition to traditional academic courses. In vocational programming, students develop specialized skills that are helpful when trying to integrate into the community following school. Although this act did not target individuals with mental or physical handicaps, it was an important precedent for laws that followed. Later legislation extended this focus to students with handicaps including mental retardation (Bowen, 1996).

Institutions

The first institution for individuals with mental retardation or psychiatric problems was founded in Massachusetts in 1848, as a wing of a state school for the blind. From that point until 1967, institutions grew to become the primary residential facilities for mentally retarded individuals. Institutions housing individuals with MR operate under the medical model, and they have tended to view their residents in a more custodial than rehabilitative manner. Institutional services do not approximate the real world by any means (Brolin, 1976).

Institutionalization of most individuals with mental or physical disabilities was not uncommon. Institutions have been defined in various ways by individuals such as Wolfensberger (1972), Clements (1976), and DeJong (1979). There is a lack of consensus on one single definition. A common theme found in all three definitions, however, was that it was a type of residence or placement that was isolated from the outside world and was not chosen by the individual who stayed there (Bruininks & Lakin, 1985). Often, institutional staff exercised a substantial measure of social control on inmates, with little outside interference. Within these institutions compliance was valued, and individualistic behavior was

often discouraged. Also, patients were often not required to perform even basic activity of daily living (ADL) or instrumental activities of daily living (IADL) tasks such as dressing, bathing, showing responsibility for self-medicating, or making decisions that would be necessary in the outside world (DeJong, 1979).

Although many patients were not discharged from these institutions, some were allowed to return to the community if they had a high level of independence while in the institution. In this case, the patient was expected to automatically assume control of his or her own health care and life decision-making. These individuals were often doomed to failure outside of the institution as they did not have these skills (Bruininks, et. al., 1981).

Deinstitutionalization/Mainstreaming/Integration

For developmentally delayed individuals, the transitional movement had been variously called deinstitutionalization, mainstreaming, or integration into the community. The different terms are used in various elements of the process, in different systems, and by different authors and policy makers.

Deinstitutionalization refers to the relocation of developmentally delayed individuals from large, centralized, isolated hospitals or state schools into the community, with services focused on and located in the community. Community housing is typically smaller and more personal. Mainstreaming is an educational movement where handicapped students are educated within regular classes with 'normal' students, instead of in segregated schools or classrooms. Integration is used where severely handicapped individuals attend school with other non-handicapped youth. They often share the same physical facilities, and they may

Transition

In order for these institutionalized individuals to be integrated successfully into the community, there became a need for transitional services. Transitional services are defined as activities designed for an individual in an effort to prepare them for the next part of his or her life goals (Brollier, et. al., 1993). This is done through the provision of vocational training, integrated employment or supportive employment, continuing education courses, independent living services, and community participation activities (Brollier, et. al., 1994).

Of these programming options, the most developed and studied is vocational programming. Vocational transition for individuals with moderate to severe disabilities has become a national priority due to the Office of Special Education and Rehabilitative Services (OSERS), with the passage of multiple federal laws funding these initiatives (Brollier, et. al., 1993). Educational legislation for the handicapped in 1983 and 1986, mandated secondary education and transition services for youth with disabilities who were between the ages of twelve and twenty-two. These amendments also mandated that federal money be spent on research of the transitioning process. In addition, the Carl D. Perkins Vocational Education Act of 1984, provided funding of vocational education and demanded that parents be made aware of vocational opportunities for their child one year prior to receiving transitional services. In 1990, with the passing of the Individuals with Disabilities Education Act (IDEA), transitional services and assistive technology were specifically defined within special education services,

and they had to be included in a disabled individual's education program (Brollier, et. al., 1993).

Vocational Rehabilitation

The year 1960 proved to be a turning point for occupational therapy and the development of services for mentally retarded individuals that focused on prevocational exploration and training techniques (Ogden, 1985). Prior to the 1960's, the focus in occupational therapy was primarily on handicapped individuals within the normal range of intelligence. One act that increased services for severely disabled and socially handicapped individuals was The Vocational Rehabilitation Act of 1973. This act defined work as the sole criteria for adjustment into the community, and vocational training had to be accessible to all students within the school system (Ogden, 1985). Funding became available for the construction of vocational rehabilitation centers and curative workshops. This allowed for increased accessibility to vocational rehabilitation programs. One downside to this Act was that it allowed states the right to determine if a client could have enough skills to be employed by the age of eighteen. If deemed inappropriate, the client could be dropped from programming (Kirkland & Robertson, 1980).

The Vocational Rehabilitation Acts were amended in 1973, with several changes relevant to vocational and community programming for the retarded (Brolin, 1976). Under this amendment, independent living services were included. These services were to be provided "to those individuals for whom a vocational goal was not possible or feasible" (DeJong, 1979, p. 437). This was an

important breakthrough in the sense that it mandated that individuals with severe handicaps receive first priority for independent living services. It also mandated affirmative action programs for the employment of the disabled, and it banned discrimination on the basis of handicap in any program or activity that received federal financial assistance. Clients were also encouraged to be involved in the design and delivery of vocational rehabilitation services. Emphasis was placed on designing programs that offered a wide range of services for individuals with disabilities (DeJong, 1979).

Research carried out in the seventies revealed that existing medical and vocational programs were not meeting independent living needs of the mentally retarded (Padavan, 1986). These studies became the impetus for the funding of independent living centers by the federal government. This led to the passage of the 1978 amendments to the Vocational Rehabilitation Act with the passage of PL 95-602. The definition of 'work' under this amendment was expanded to include the development of improved social skills, use of leisure time, and the acquisition of personal skills leading to expanded personal independence. Independence training could now be included in the goals of the rehabilitation process (Baum, 1980). PL 95-602 mandated that independent living centers for severely handicapped individuals be funded with federal money. According to Carolyn Manville Baum, the passage of this amendment was "the reason independent living centers were established [due to the passage of this amendment]" (Baum, 1980, p. 773).

Following this amendment, the number of independent living centers in the United States increased from an estimated fifty-two centers in 1977, to over 300 in 1986. This number is still on the rise (Nosek, et. al., 1990). Current independent living centers offer a variety of services for the disabled individual. These services include independent living skills training, assistance with housing and transportation, information and referral, attendant-related services, self-advocacy, peer counseling, and vocational training. Many of these services fall within the scope of occupational therapy, however, only forty-six percent of the independent living centers in the United States offer occupational therapy services (Bowen, 1996).

The Vocational Rehabilitation Acts were the major source of funding for vocational and community independent living programs for individuals with MR (Nosek, et. al., 1990). Vocational education services that were funded include: special instructional programs, prevocational orientation programs, vocational counseling, and employability skills training. It is felt that these services enhance the opportunities of handicapped individuals in a vocational education program (Brolin, 1976). The Vocational Rehabilitation Act and its amendments have also brought about an increase in societal awareness about housing and employment issues faced by physically or mentally disabled individuals. An increased focus on skill acquisition and advocacy for individuals with disabilities has become a priority.

Educational Reforms

Along with the developments in vocational rehabilitation, parallel reforms occurred during the same time period in the education of handicapped children. In 1975, with the passage of the Education for All Handicapped Children's Act, PL 94-142, students with disabilities were mainstreamed into regular education. Rather than separating individuals with handicaps from normal children in the school setting, there was a push to integrate children with disabilities into a classroom with normal children of the same age. Parents and children were also given the right to a free, appropriate public education that included related services such as occupational therapy (Ogden, 1985). If the local public school district was unable to provide needed services, the district was forced to cover the cost of private tuition for the disabled individual at a school that did offer services.

As part of the mandate for an appropriate education, the child's education plan is expected to include vocational and activity of daily living goals. The individualized education plan (IEP) was introduced. This permits parents, teachers, and other professionals to develop a plan based on the particular child's wants and needs. This act has since been amended under PL 101-476, Individuals with Disabilities Education Act (IDEA). IDEA expanded the rights of parents of disabled children. Part of PL94-142 under these two laws, parents were given the right to have their child evaluated in all areas related to the disability so a program could be tailored to the child's specific needs. The child could also be placed in

the least restrictive environment (LRE) so that they could be challenged, but not overwhelmed by the learning environment. (Kirkland & Robertson, 1980).

With the passage of PL94-142 and IDEA, there has been a movement away from teaching only academics, and progressively more emphasis has been placed on an education that was appropriate for the specific child. This includes the requirement for assessment and planning for vocational programming and transitioning to be done well before graduation.

Nearly ten years after the passing of PL 94-142, the Carl D. Perkins Vocational Education Act, PL 98-524, was passed in 1985. The purpose of this act was "to assure that individuals who are inadequately served under the vocational education programs are assured access to quality vocational education programs, especially individuals who are disadvantaged, who are handicapped, men and women entering nontraditional occupations, adults who are in need of training and re-training, and individuals who are incarcerated in correctional institutions" (President's, 1999, p. 1). This law mandated services and funding for vocational education of underserved, including mentally handicapped adults. It supported and reinforced the importance of vocational education. It also led to an increased awareness that planning for transitioning is necessary if an individual is to succeed in the community (President's, 1999).

Housing Options

Community residences emerged as a response to the nationwide deinstitutionalization movement began in the 1960's. During this period, public and professional opinion focused increasingly on the negative effects of

institutions for the mentally disabled, and on ways to allow these individuals to live in a more appropriate setting (Padavan, 1986). There are a variety of special housing options potentially available to the handicapped. The different types of housing available in the community take into account the differences in independence potential across disabilities. These include, but are not limited to, group homes, independent living centers, transitional living/supported apartments, supported living/live-in help, foster care, living at home with family, independent apartments or homes, and shared housing (McCarron & Dial, 1991).

The group home is one housing option (McCarron & Dial, 1991). This option has more than two hours but less than twenty-four hours of supervision and support, and primarily addresses IADL needs. An individual living in a group home may usually hold a job in the community with support, can participate in social activities such as dating, and is typically able to use community transportation and other resources independently (McCarron & Dial, 1991). A group living program has mandated regulations concerning how the home is run. These regulations include who is eligible to live in this setting, how many people can live there, and how the house is staffed (Smith, 1998).

A second housing option that is often used is an independent living center. This type of housing is different from the group home, because residents in this setting require a greater amount of supervision. Residents live in small apartments within the center. There are staff and support services on site twenty-four hours per day, and residents receive supervision as needed. It is a place for mentally and physically handicapped individuals who need to develop skills and

strategies for independent living. According to the 1978 amendments to the Rehabilitation Act, "to be considered an independent living center, attendant care, peer counseling, independent living skills training, and assistance with housing and transportation must be among the services provided" (Bowen, 1996, p. 22). In 1996, only forty-six percent of the independent living centers in the United States used occupational therapy services, and the centers that did provide OT services only did so at an average of seventeen hours per month (Bowen, 1996). The centers that did offer OT services were those that had a broader spectrum of services including assistive device provision and daily living skills training.

A third living arrangement is known variously as transitional living or supported apartments. This housing option is for individuals who are able to live independently but may require some amount of counseling intervention. Clients live in their own apartments. Staff is available when guidance is necessary. This type of housing includes arrangements for counseling intervention that may be needed to help with community interaction when necessary (McCarron & Dial, 1991). Staff is not required on the housing site but is available to help with emergencies. Individuals living in this setting are generally employed in the community (McCarron & Dial, 1991). The amount of service varies greatly within this type of setting, and careful investigation is imperative before a choice to live in this housing arrangement is made (Trombly, 1995).

Supported living with live-in help is a fourth option for individuals with handicaps wishing to live in the community. This housing situation involves having a live-in aide who is available continuously in the home around the clock

to perform instrumental activities of daily living such as cooking, cleaning, laundry, money management, shopping, medicine management, etc. This arrangement takes some responsibility away from the disabled individual and places more on the live-in aide (McCarron & Dial, 1991).

Foster care is also a possibility for individuals who are interested in independent living, but need various levels of supervision. In this housing arrangement, a family other than relatives is usually paid to allow one or more individuals to reside in its home. The individual may be treated as a member of the family with rights and responsibilities, or he or she may be treated as a boarder and be expected to be completely independent. The amount of assistance and press for independent behavior varies markedly in foster care (Collins, 1997).

A newer approach to community living is shared housing. This consists of a symbiotic relationship between an elderly individual who wishes to remain in his or her home, but who cannot for medical or safety reasons live alone; and an individual with physical or mental disabilities who also cannot live alone but is capable of performing basic ADL and IADL tasks such as cooking, cleaning the house, or even taking care of himself/herself or others (Collins, 1997). Together, these individuals are able to live in a situation that provides joint benefits.

A shared housing project that was developed in New Orleans, uses the idea of a complementary relationship when matching the homeowner and the home seeker. Marion Strauss, program developer, has stated that shared housing can be highly successful when a correct match is made between the needs of the elderly person and the mentally or physically disabled individual. One example is

Shared Housing of New Orleans, Inc. (Collins, 1997). The potential of this program has been demonstrated through case studies done within this shared housing organization, which has been operating since 1988. One example provided is a mutual support situation where a seventy-eight year old woman with a slow-healing broken hip and the inability to fully perform home maintenance activities was matched with a fifty-four year old woman with agoraphobia and panic attacks. These individuals were able to help each other and maintain a nurturing relationship for two years (Collins, 1997). Another successful example was a match made when an eighty-three year old blind woman who spoke very little English and needed only short-term help for activities such as house cleaning and reading her mail. She was matched for six months with a sixty-three year old woman who had suffered a stroke but was able to perform most activities of daily living such as dressing and house cleaning. The new roommate was able to provide the short-term assistance needed while being provided a house with security and companionship. In both cases, shared housing helped to keep people in their homes and out of nursing homes, and it has offered mentally or physically disabled individuals a place to live and put their skills to work (Collins, 1997).

The final and most independent type of housing available to mentally and physically handicapped individuals is independent living in a private home or apartment. This is autonomous living in the community without the need for supervision or assistance (McCarron & Dial, 1991). This is an option for individuals with mild or even moderate MR, provided they have the required independent and instrumental living skills.

Fair Housing Act

Even though different housing options are supposed to exist for individuals with mental retardation, many barriers remained such as discriminatory attitudes within the community. To counter housing segregation and discrimination, the Fair Housing Act (FHA) was passed to protect people who were refused housing, or modifications to housing on the basis of race, gender, or disability (Fair, 1999, p.4). The 1988 amendments to this act mandated that housing be open to all individuals, and that reasonable modifications be made for handicapped individuals.

The main needs for most people with disabilities are housing and help with daily living. Without suitable housing, community care for disabled people is doomed to failure (Swain, 1993). Under the Fair Housing Act, reasonable accommodations and modifications included such things as the installation of a ramp, especially if the individual has a wheelchair or walker; installation of grab bars, whether they be outside near stairs, or inside in hallways or bathroom facilities; widening of doorways in order to allow a wheelchair or other necessary equipment to pass through; or installation of a lift (Fair, 1999).

In most cases, the tenant still pays for modifications needed. The tenant would also oversee these changes in order to ensure that the work was done properly, and that the proper permits were obtained (Fair, 1999). With the passing of the Fair Housing Act, and an increased availability of housing, many mild and moderate mentally retarded individuals have the ability to live independently in modified community housing. With this increase comes the

need for transitional programming that goes beyond vocational training to independent community living (DeJong, 1979).

Occupational Therapy's (OT's) Role in MR Programming

Independence is a concept highly valued by occupational therapists. In fact, most occupational therapists would probably agree that a primary goal of their practice is to assist others to live as independently as possible. Throughout history, occupational therapists have applied this idea of independence when treating patients, whether in an institutional setting, a hospital, or a school. OT's have worked with individuals having MR for many years in an effort to increase their independence and develop functional skills. Prior to the seventies, OT's commonly worked within institutional settings. They have shifted to working in schools with the push for deinstitutionalization and handicapped education in the 1970's. There is now an increased focus on practicing OT out in the community as well as within the school system (Law & Mills, 1998).

As a related service, OT supports the special education of the handicapped child (Law & Mills, 1998). Initially, most focus of school-based occupational therapy (SBOT) was placed on developing self-care, school-related skills, and components such as writing or perception. As the changes in special education have occurred, OT focus also has the potential to change. Occupational therapists may provide valuable assessment, training, and consultation in transitional and vocational areas as well. A potential need still exists for adolescent preparation for work or independent living. Occupational therapists can be good integrative people when working with individuals who are in special education and

vocational education. This is because they focus on role performance as well as an understanding of disability (Kirkland & Robertson, 1980).

According to Kirkland and Robertson, 1980, most occupational therapists still work with adults, however, there is an increasing need for occupational therapists to work with adolescents who are in need of vocational rehabilitation and transitioning into the community following high school (Kirkland & Robertson, 1980). "During the 'student role' years, considerable effort should be directed to adapting to social and occupational roles, building skills and habits for successful living, preparing for responsibilities of citizenship, and exploring avenues for achievement" (Kirkland & Robertson, 1980, p. 24).

There is a broad scope of OT services that can be offered to adolescents and adults with MR. Traditionally, OT's worked with posture, developmental skills, and feeding, however, recent roles have expanded to include work programming and evaluation, preparation for community living, and IADL training. These services can be offered either while working directly or on a consultative basis with the handicapped individual who is still in school, as well as when they have completed school and are able to work in sheltered workshops or in an occupational therapy mandated day treatment service in New York State or a supervised work setting.

Occupational Therapy Theory

Multiple theories of occupational therapy have been applied when working with mentally retarded individuals (Blodgett, 1971). Traditional programming has tended to focus on developmental, rehabilitative, and

acquisitional behavioral models. The developmental model is concerned with the acquisition and changes in skills over the individual's life span. It sees these behaviors as progressing naturally from one stage to another as the individual ages. There are normal behaviors expected at each age level within this model. It is the responsibility of the occupational therapist to evaluate whether the individual is performing the activities expected for his or her age and stage. Remediation is designed to remove blocks in normal development by building skills that precede and provide a foundation for higher-level skills. Under the developmental model, it is believed that there is a natural progression of skill development. Lower skills develop and then lead to the development of higher-level skills and this is done in a specific sequence (Trombly, 1995).

Within this model, it is important to realize that both growth and decline are developmental processes that operate throughout the lifespan, and not only in the childhood years. This model assumes that the MR client will and should go through the same stages as normally developing individuals. It is important to progress beyond early skill development to age-appropriate and useful independent living skills (Kurtz, et. al., 1996).

The rehabilitation model is utilized in both medical and vocational rehabilitation. Dysfunction is generally described as inadequate performance in ADLs or in terms of inadequate preparation for employment (Hopkins & Smith, 1993). One problem with this model is that it is the individual who is considered dysfunctional. In order to reach a state of function, the problem within the individual must be resolved. A handicap such as MR, impairs the person's ability

to meet life demands. Treatment focuses on meeting these demands through specific skills training, and accommodation of the task through the use of adapted equipment. This is often done when the individual assumes a submissive role by following the instructions of a therapist or other professional in order to reach maximum functioning (DeJong, 1979).

Acquisitional or behavioral models focus on specific aspects of an individual's behavior that are in need of correction and attention. The core concepts were based on theories of experimental psychologists such as Pavlov, Thorndike, and Skinner (Hopkins & Smith, 1993). According to this approach, learning occurs through interaction with a reinforcing environment and learning is the basis of all behavior. If an individual is lacking specific skills, it is said that they have poorly adapted to the environment. If this occurs, instruction is necessary to form more adaptive behaviors so an individual can function in activities of daily living, work, and leisure. This can be done by shaping, positive or negative reinforcement, chaining to learn the basic components of a skill, practice, task analysis, or feedback. Treatment focuses on the use of rote activities, practice, repetition, training, and reinforcement. A person is considered to have achieved a state of function within this model when he or she attains the appropriate kinds and amounts of functional skills to acquire independence within the environment in which he or she resides (Hopkins & Smith, 1993).

Each of these models has individual strengths and weaknesses. They have all been researched thoroughly. They have also been among the traditional theories most often used by occupational therapists. When examined critically,

the developmental model is limited when addressing adult developmental cycles, because it primarily focuses on the developmental cycle of the child. All three of these approaches tend to be limited in that they focus on the parts of a person, rather than seeing the individual as a holistic being with other interrelated factors that affect his or her performance.

More recent theoretical approaches provide a more holistic and systematic view of the person. These models include the Occupational Behavior (OB) and Model of Human Occupation (MOHO), the Person-Environment-Occupational Performance Model (PEO), and a Client-Centered Approach. The idea behind Occupational Behavior and the Model of Human Occupation was fostered in the early sixties by Mary Reilly (Christiansen & Baum, 1997). She asserted that only with balance between work, rest, play, and sleep was healthy living achieved. The person is seen as a system that takes in information from the outside world, incorporates that information, and then uses it to produce a desired result. Individuals with mental retardation often need additional information or cues from the environment in order to process the information from the outside world to reach a desired outcome. OB and MOHO also focus on an individual's motivation to complete an occupation whether it is in the form of work, play, rest, or leisure. It takes into account the patterning of behavior into routines, and the effects the environment has on an individual's functioning. Routines are often a key part of occupational therapy training and treatment when working with MR clients (Brolin, 1976). Work and play are considered to be the basis for skill acquisition and role development throughout life. Within this model, a person is

felt to be dysfunctional when there is a disruption in any part of the system including roles, habits, or any part of the person's occupation and remediation focuses on one or more parts of the system to allow satisfactory performance of life roles (Christiansen & Baum, 1997).

The Person-Environment-Occupation Model focuses on the match between the person and the environment. According to this model, "occupational performance is always influenced by the characteristics of the environment in which it occurs" (Christiansen & Baum, 1997, p.61). The three major components of this model include what people do in their daily lives, what motivates them, and how their personal characteristics combine with the situations in which occupations are undertaken (Christiansen & Baum, 1997). This view postulates that people are naturally motivated to explore their world and environment, and to demonstrate mastery within it. A state of dysfunction exists when an individual is unable to experience success within the physical or social environment. This model, too, focuses on performance of life tasks and roles. The accessibility of jobs, transportation, and housing are all considered within this model, as well as the social acceptance of individuals with disabilities.

The Client-Centered Model of occupational therapy is a Canadian model of practice that has been defined as "an approach to service which embraces a philosophy of respect for, and partnership with, people receiving services" (Law, 1998, p. 3). It promotes client participation, exchange of information, client decision-making, and respect for the choices that the individual makes. The focus is on finding meaning in everyday occupations. It also places an emphasis on the

role spirituality can play in an individual's life. Dysfunction occurs when an individual is unable to find satisfaction in everyday activities, or he or she is unable to perform occupations that are meaningful. In this model, it is important to look at and treat the issues that are important to the client. Individuals with disabilities may have a wide range of needs as seen by an occupational therapist, however, these needs are only addressed if they are first perceived to be important by the client (Law, 1998).

These models are similar in many ways. There is a respect for clients, their families, and the choices they make. Clients and families have the ultimate responsibility for decisions about daily occupations and occupational therapy services addressed. Provision of information, physical comfort, and emotional support are important across all of the models. In each, occupational therapy service delivery is individualized and flexible to the client's needs. Clients are encouraged to solve occupational performance issues independently or with coaching from the OT. There is also a focus on the effects of the person-environment-occupation relationships in each view. Finally, each focuses on the individual's personal life, work patterns, and roles (Law, 1998).

These newer models tend to incorporate individual roles and the environment. They have taken the best features from the more mechanistic models, and have focused on a more client-empowering approach. They can be overwhelming, because they are broader and less specific than their predecessors. Additionally, some of the above models are not yet fully developed, and they need additional development and research. However, they do seem to be more

appropriate to transitioning and the mentally retarded population than the more traditional theories formerly used. All of the models consider the individual's needs and wants, and they encourage adapting the environment so that these needs can be adequately met. These models realize that there are different motivating factors, and all individuals are unique. Therefore, treatment planning needs to be individualized to the client, in order to foster the most growth and success in treatment.

Using these models, the occupational therapist has an understanding of the tools and roles needed to assist in the transitional process. Roles for occupational therapists are multifaceted. OT's have the ability to modify and structure the physical, social, and temporal environments so individuals with MR can develop the self-care, home management, work, school, and leisure skills necessary to live and work independently in the community (Brollier & Shepherd, 1993). Transition programming is an on-going, outcome-oriented process that includes a commitment of resources, collaboration between people and agencies involved with the individual, and decision making in order to develop individualized plans for the client (Ogden, 1985). Occupational therapists can facilitate the transition process for individuals with disabilities when they concentrate on real-life functional activities and the specific needs of the client (Brollier & Shepherd, 1993).

Transitional Programming

There are several key elements to transition programming. To function competently within community settings, individuals with MR must demonstrate a

wide array of skills. The skills needed range from basic self-care to complex interactions with a variety of people in social and vocational contexts, all of which are within the scope of OT. According to Bruininks and Lakin, (1985), skills that should be included in transition programming include daily living skills such as dressing, feeding, and grooming. These ADL's become increasingly important as individuals age. Being able to properly dress and groom oneself is necessary for social and vocational reasons, and it is often a prerequisite for obtaining and maintaining a job.

Functional academic skills are another area considered to be significant in the transitional process (Bruininks & Lakin, 1985). Basic math, reading, and writing abilities are needed when reading mail, signing documents, taking medication, and managing money. These skills all become important as an individual nears the completion of schooling. Personal-social skills also develop while an individual is in school. The ability to communicate effectively can be especially important during adolescence when an individual is trying to make friends or communicate with peers. Social skills are also vital out in the community when using public transportation, working at a job, and shopping at a grocery store. (Bruininks & Lakin, 1985).

The final areas that Bruininks and Lakin (1985) felt were needed in transitional programming include vocational guidance and preparation for work. These are the most commonly accepted and included skills in transition programming. Individuals with MR often have the capabilities to learn skills that can be carried over to either sheltered workshops or community employment. It

is essential that prevocational skills be taught in transitional programming so they can be used following the completion of school (Bruininks & Lakin, 1985).

Luecking and Fabian (1997) have found that successful transitional living programs have common values that underlie the skills that are taught. Included are the belief that consumer input is important at all stages of transition planning and treatment should be driven by the client. Services should focus on meeting consumer's individual needs rather than just fitting a client into a predetermined format, and the physical and social environment in which the individual lives needs consideration. There must also be a strong commitment to transitioning and community integration, positive relationships and networking with local businesses as well as creative job development to promote success. Finally, there must be a recognition that transitioning is a life long process that does not stop once an individual has been placed in a job or has housing (Luecking & Fabian, 1997).

Occupational therapy subscribes to these values. In transitioning, OT focuses on the needs of each individual client, and care is centered on what the person with the disability feels is important. The planning process begins with the individual, and OT programming concentrates on developing personal relationships, positive roles in the community, and skills for self-empowerment. It is the role of the OT to foster growth and ensure the development of skills to achieve the desired client goals.

An often-overlooked area that is also important when teaching transitional living skills is generalization. Independent community living requires the

individual to be competent in a variety of settings that always have the potential for change. The individual must be able to respond appropriately to new situations by generalizing skills learned in another context (Bruininks & Lakin, 1985).

Students with disabilities may have a difficult time deciding what they want to do beyond high school. Transition planning can make the change easier for both the student and his or her family, and occupational therapy can play a key role in this process. Programs in OT can facilitate transition from one system such as school to another such as independent community living (Ogden, 1985). This can be done through the adaptation of social and occupational roles, the building of skills and habits for successful living, the preparation for responsibilities, and the exploration of possible avenues for achievement (Kirkland & Robertson, 1980).

The transitional process is consistent with the theory and practice of OT. Occupation can be viewed as the dominant influence on the success of the work role for disabled people, and the use of occupation is an important tool for occupational therapy practice (Kirkland & Robertson, 1980). A lot of programming work still remains to be done in the area of transitioning. Little is known about the extent to which OT's work in transitioning and what their roles, attitudes, and beliefs are regarding the impact that transitioning has on OT consumers. Therefore, it is the responsibility of OT personnel to understand the unique aspects of the transitional process and to integrate OT into this service to better serve individuals with MR (Ogden, 1985).

Conclusion

There is a clear need for the development of skills for independent living and work for individuals with mental retardation who cannot easily acquire or generalize these skills. Special training is needed to assist in this transition.

There is a potential role for OT's in assisting individuals in the development and transfer of skills. There is a need to know what OT's are and what they could do in this process.

Based upon review of the research and literature in this area, it is apparent that additional research is needed in the area of independent living for mentally retarded individuals. Minimal information is available concerning the effectiveness of OT's in the process of transitioning consumers, primarily individuals with MR or DD. Although many laws have been passed to ensure equal rights and education for individuals with MR or other disabilities, more information is needed in transition planning and programming. The current trend in politics and funding is to integrate these individuals into the community, but there is minimal research done to show how this can be done most effectively in regards to employment as well as independent community living. Research is needed to find out whether there is a type of transitional programming that would work most effectively with mentally retarded individuals to ensure their success following high school.

OVERVIEW

The purpose of this study was to examine the roles and perceptions of occupational therapy personnel regarding transitioning. This was done via a mail survey of American Occupational Therapy Association members living in New York State.

Research Participants

The participants in this study were 150 occupational therapy practitioners who work within New York State, who were also members of the American Occupational Therapy Association's (AOTA) Developmental Disabilities Special Interest Section (DD SIS). All participants were eighteen years or older. One hundred fifty participants were selected at random to take part in the study from a mailing list of two hundred individuals provided by the AOTA. Both occupational therapists (OT's) and certified occupational therapy assistants (COTA's) were included in this research.

Description of the Survey Tool

A survey was developed specifically for this research (Appendix A). The instrument was developed by this researcher based on information obtained from an in-depth literature review, as well as advice from occupational therapy faculty and occupational therapy graduate students at Ithaca College.

The research tool consisted of a survey questionnaire of twenty-four questions titled, "Transitional Living Survey." The tool was designed to collect data on occupational therapy personnel and their feelings about transitional living programs. The survey included several items cited by previous researchers as being

pertinent in previous vocational and community transition research. Based on the literature review, the following issues were addressed: respondent information, facility information, consumer population, community resources, and transitional programming. According to a study done by Sale (1998), these areas are important to consider when developing a program that works to transition individuals into the community. These areas became the headings for each subsection of the survey. Table 1, below, contains a brief overview of the survey questions, their corresponding subject areas, and data types.

A study done by Arnold and Seekins (1998), found the following questions to be important when assessing differences between rural and urban vocational rehabilitation programs: demographic items pertaining to location, education, establishment of the facility, funding, and client population. These issues were addressed in questions one through eleven of the survey. The study also indicated that the following questions were also of importance: Do local employers hire people with disabilities? Are job service coaches available in the area? Is counseling available? Is assistive technology accessible? Is it important to develop an initial rapport with customers? (Arnold & Seekins, 1998). These issues were addressed in questions twenty and twenty-four.

Questions one through eight examined participant demographics. This included questions such as current job title, years worked under this job title, education level, certifications held if any, years practiced at current facility, and the occupational therapy theories used by the participant when working with clients. Questions nine through eleven examined facility demographics - How long has the

TABLE 1. Overview of Survey Questionnaire

<u>Question #'s:</u>	<u>Subject Area:</u>	<u>Data Type:</u>
1, 3, 4b, 6	therapist demographics (title, education, certifications, hours)	nominal
2, 5, 7	therapist demographics (experience, years, hours/week)	ratio
4a	therapist demographics (certifications)	nominal
8a	theories used	nominal
8b, 11b, 12b, 19b	theories, funding, consumer population, settings (top three ranked in order)	ordinal
9, 10, 11a	facility demographics (years established, community, funding)	nominal
12a, 13, 14	consumer demographics (population, ages, gender)	nominal
15	consumer demographics (% MR/DD)	ratio
16	professions on team	nominal
17	work in transitioning	nominal
18, 19a	community resources (transportation, housing)	nominal
20, 22c, 24	transitional programming (assessments, statements)	interval
21, 22b	transitional programming (treatment, assessments used)	nominal
22a, 23a	transitional programming (use of assessments, skills taught)	nominal
23b	transitional programming (perceived importance of skills)	interval

facility been established? In what type of community it is run? What are the primary sources of funding for the facility? The consumer population was discussed in questions twelve through seventeen. This included questions about the population served by the facility, the age ranges and gender of the consumers served, and the percentage of individuals with MR or DD who are treated by the facility. Questions about professions and settings included: What other professionals serve the consumer? Is transitioning integrated into the consumer's treatment planning?

Community resources were discussed in questions eighteen through twenty, where questions were raised about the availability of transportation and current living arrangements for consumers. Question twenty consisted of ten statements about availability of resources, and it asked the participants to indicate their position on a bipolar continuum between "strongly agree" and "strongly disagree." The continuum contained five points with a "neutral" response in the middle. The interval between each point on the continuum was assumed to have equal weight, thus creating a Likert scale and allowing data comparison (Cash, 1992). To maintain reader interest, the wording for each statement was different, requiring the subject to read each question carefully. Within question twenty, letter (h) was worded negatively to interrupt the wording pattern of the previous statements (Cash, 1992).

The last subject area addressed in the survey was transitional programming, in questions twenty-one through twenty-four. This section looked at the role of the occupational therapist when working with the consumers and whether any

standardized assessment tools were used to evaluate and re-evaluate consumers.

In survey question twenty-three, under the heading of transitional programming, the participants were asked to look at twenty-eight occupational performance areas and state either "yes" or "no" to the question: "Are the following skills taught in your facility?" The participants were then asked to rank these same skills on a scale of one to ten based on its perceived importance for independent living.

Question twenty-four under this heading consisted of a number of statements that were worded both positively and negatively. The participant was asked to respond to the statements based on the level of agreement ranging from "strongly agree" to "strongly disagree." Again, the intervals along this scale were considered to have equal weight, thus creating a Likert scale similar to question twenty.

Pilot Study

Prior to sending out survey packets, a pilot study was completed. A total of thirteen individuals completed the pilot questionnaire. Four occupational therapy graduate students, eight occupational therapy faculty members, and one community occupational therapist working in transitional programming were asked to look at the preliminary survey. They were informed that the questionnaire was a pilot study, and they were asked to give suggestions on any questions that were unclear or inappropriate. The researcher indicated that she was interested in their comments and/or suggestions. They were asked to make any corrections needed or to propose additional questions to the survey if they felt it was lacking in a particular area.

One common suggestion given by both students and faculty included providing additional choices to questions, defining certain choices such as current housing, and adding additional questions that asked what the primary answer would be if given the option to 'check all that apply.' All suggestions were considered and editorial changes were made following the field test. The final survey included these changes.

Data Collection

Survey packets were mailed on March 1, 2000, to individual occupational therapy practitioners at their home addresses. This packet included a cover letter that explained the survey, the informed consent form that had to be signed and returned in order for the individual to participate in the study, and permission for the information given in the survey to be used by the researcher (Appendix C).

Also included was the final survey (Appendix A). In order to maximize the return rate, all individuals who returned the survey by March 10, 2000, and filled out a drawing information sheet (Appendix C) with their name, address, daytime and evening phone numbers, were eligible for a \$50.00 savings bond. Also included was a pre-addressed stamped envelope. All survey packets had the return address of Ithaca College Occupational Therapy Department.

On March 8, 2000, a reminder letter (Appendix D) was mailed to individuals from whom the researcher had not yet received completed surveys. This letter asked the participants again to complete the survey and return it by March 28, 2000. If these individuals had any questions about the survey or needed

another copy, a phone number was given where the researcher would be available to answer questions.

With 150 surveys mailed out, it was hoped that the return rate would be at least thirty per cent, or an estimate of forty-five surveys. In an effort to increase this response rate, an inducement of a \$50.00 savings bond drawing was offered to participate in the study. Each survey packet that was mailed had a drawing information sheet attached to it.

Confidentiality and Separation Procedures

In an effort to maintain anonymity of all individuals participating in the study, all returned surveys were separated from both the letter of informed consent and the drawing information sheet. The survey was then labeled with a number for the purpose of data collection and analysis, and then kept in a folder. The letter of informed consent was used to mark off the individuals who had returned surveys, and it was then kept in a separate envelope along with the initial mailing list. The drawing information forms were placed in a box until the date of the drawing (March 10, 2000). Following the drawing, the drawing information sheets were placed in the envelope with the informed consent forms where they remained separate from the actual surveys.

Data Compilation

The responses obtained from the questionnaires were entered into an IBM compatible computer using Statistical Package for Social Sciences, (SPSS). Cells with unanswered questions were left blank. Partially completed surveys were

included in the study. The SPSS software was used to complete all statistical calculations. Handwritten, open-ended responses were tabulated and categorized by the researcher.

Data Analysis

Descriptive statistical techniques, including mean, median, mode, percentage, and cross tabulations were used to analyze and describe the data through the use of the SPSS computer package. Frequencies and descriptive statistics were calculated for all questions. Analysis of potential relationships was done via cross tabulations. Comparisons were made based on items such as job title, center type, and center location. Tests for significance were not carried out due to the small size of data cells and the number of surveys returned. Analysis was done concerning the research question: "When teaching transitional living skills, are there key elements that determine whether a mentally retarded individual will experience success in independent living?" This question was evaluated based on which specific elements of the occupational performance list continued to be rated as more important than other elements. Other data such as demographics were analyzed to determine whether differences exist between what therapists in rural settings perceive as important compared to therapists in urban settings.

Scope and Limitations of Study

This study only looked at how occupational therapy personnel in New York State felt about transitioning, and did not evaluate the effectiveness of their programs. Only occupational therapy practitioners who were on the Developmental Disabilities Special Interest Section List of AOTA participated in

this study. This ruled out any occupational therapists who work in transitioning but who are not members of AOTA or of the special interest group. Similarly, not all occupational therapy personnel who were sent surveys work in the transitioning of their clients, and therefore some surveys were not fully completed. Finally, the study did not specifically examine the potential roles for an occupational therapist that are now carried out by other professionals or non-professionals.

RESULTS

Descriptive Data

Response

The survey questionnaire, (Appendix A), was mailed to one hundred fifty occupational therapy personnel, randomly selected within New York State, as per the method described in Chapter Three. A total of thirty-eight surveys were returned; twenty-six after the initial mailing, and twelve following the second mailing. One of the thirty-eight respondents indicated that she no longer worked in the field of occupational therapy, and returned the questionnaire blank. The remaining thirty-seven responses were used in data calculations.

According to Bailey, (1997), the average return rate for surveys is 35%, therefore it was expected that out of the 150 surveys that were properly routed, sixty-two of them would be sent back. The actual return of only thirty-eight surveys or twenty-five percent fell well below the average return rate for surveys and the research expectations.

Description of Subjects

The survey questionnaire was mailed to a subject population that was approximately 12% males, and 88% females (gender was determined via their given names). Of the thirty-eight respondents, 13.5% were males, and 86.5% were females. Thirty respondents currently practice under the title of licensed occupational therapist, six were certified occupational therapy assistants, and one was the director of industrial rehabilitation. Eight of the licensed occupational therapists have professional certifications in addition to their primary title. These include: certification in administration of the Sensory Integration and Praxis Test

(SIPT), certification in the administration of the WEEfm, certification in NDT, infant massage instructor, Board of Disability Analyst, Optician, Assistive Technology Consultant, Fellow-AM, and GMFM certified for data collection. There is quite a bit of variability in experience reported by the respondents. The work experience level of the participants averaged 8.44 years, indicating a moderate level of experience, (see Table 2 below). These individuals indicated that they have worked at their current facility an average of 6.48 years. The mean number of hours worked per week under their job title is 29.83 hours per week; most individuals are working between part-time and full-time.

Community Demographics

The primary community setting in which all of the respondents, and not just those who work in transition planning, practice is urban (thirteen individuals), suburban (nine individuals), small town (eight individuals), large town (seven individuals), rural (six individuals), and two individuals stated that they work in a setting other than the ones described above. Proportionally, more COTA's are employed in rural/small town and urban environments than in suburban or large town areas (See Table 3). All but two of the employment facilities (92.1%) were described as being established six years or more. The two remaining facilities have been established for between two and five years. Some therapists report working in more than one facility setting serving this population.

Theories Used

Thirty-seven individuals responded to the questions on theory. A variety of theoretical models are used by these OT's. By far, the most common models used are developmental. Developmental theory is used by twenty-one individuals and

TABLE 2. Participant Demographics

	Mean	n	Range	Standard Deviation
Years worked under title	8.44	36	.12-26	± 7.32
Years worked at facility	6.48	37	.12-21	± 6.16
Hours worked at facility	29.84	38	.00-48	± 11.87

TABLE 3. Job Title and Community Setting

Job Title	Rural	Small Town	Suburban	Large Town	Urban	Other
Occupational Therapist	5 (13.5%)	5 (13.5%)	7 (18.9%)	7 (18.9%)	11 (29.7%)	2 (5.4%)
COTA	1 (2.7%)	3 (8.1%)	1 (2.7%)	0 (0%)	2 (5.4%)	0 (0%)
Director of Industrial Rehab	0 (0%)	0 (0%)	1 (2.7%)	0 (0%)	0 (0%)	0 (0%)

n=37

cognitive models by three individuals. NDT and Occupational Behavior (OB) along with the Model of Human Occupation (MOHO) were each reported by two individuals, and behavioral, vocational rehabilitation, occupational science, and sensory integration by one individual each. It was found that the developmental model is used primarily with clients under the age of twenty-one. With older ages, there is a shift in models used, and more variety of models reported. This trend also held true when cross analyzing the second and third most popular theories used (See Table 4).

Team Members

Question number sixteen on the survey questionnaire was "What professions are represented on your team when working with a consumer?" Thirty-six individuals (97.3%) stated that physical therapists were part of the team. Thirty-five (94.6%) listed speech therapists. Thirty individuals (81.1%) listed occupational therapists. Twenty-three participants (62.2%) reported Psychiatrists/psychologists on the team. Educators and special education teachers were considered part of the team 54.1% of the time. Social workers and nurses were listed as team members 45.9% of the time. Other team members such as doctors, aides, service coordinators, counselors, COTA's, neurologists, vision and hearing specialists, and parents were considered to be team members by 40.5% of the participants. Nine individuals, 24.3%, identified dietary/nutrition specialists as team members. The professions that were listed as team members the least frequently were adapted physical education (8.1%), music therapy (8.1%), and therapeutic recreation (5.4%) (See Table 5).

TABLE 4. Primary Theoretical Models and the Ages Ranges in Which They Are Used

Age Ranges	Behavioral	Vocational Rehabilitation	Cognitive	Developmental	Other	OB/MOHO	Science	Occupational	Sensory Integration	NDT
0-5	0 (0%)	0 (0%)	0 (0%)	7 (18.9%)	0 (0%)	0 (0%)	1 (2.7%)	0 (0%)	1 (2.7%)	
6-12	0 (0%)	0 (0%)	1 (2.7%)	9 (24.3%)	1 (2.7%)	1 (2.7%)	0 (0%)	1 (2.7%)	1 (2.7%)	
13-20	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
21-40	0 (0%)	1 (2.7%)	2 (5.4%)	0 (0%)	0 (0%)	2 (5.4%)	0 (0%)	0 (0%)	0 (0%)	
41-64	0 (0%)	0 (0%)	0 (0%)	5 (13.5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
65 and above	1 (2.7%)	0 (0%)	0 (0%)	0 (0%)	1 (2.7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
TOTAL	1 (2.7%)	1 (2.7%)	3 (8.1%)	21 (56.8%)	2 (5.4%)	2 (5.4%)	1 (2.7%)	1 (2.7%)	2 (5.4%)	

n= 37

TABLE 5. Team Members Who Work With Consumers

Profession	Frequency	Percent
Occupational Therapy	30	81.1%
Physical Therapy	36	97.3%
Speech Therapy	35	94.6%
Social Work	17	45.9%
Psychology/Psychiatrists	23	62.2%
Nursing	17	45.9%
Educators	20	54.1%
Dietary/Nutrition	9	24.3%
Adapted PE	3	8.1%
Music Therapy	3	8.1%
Therapeutic Recreation	2	5.4%
Other	15	40.5%

n= 37

Facility Funding

Participants were also questioned on sources of funding for the facility in which they practice. Most facilities received funding from more than one source. Thirty-two OT's responded to this question, and indicated one to nine different options for source of funding. When asked for the primary source of funding, eight out of the thirty-two individuals (25%) indicated that Medicaid was their primary source of funding, 40% chose it as their second most common funding, and 14.3% stated that it was their third most common source of funding. State MR was the next most frequent option selected by 18.8% of the participants as primary funding source. It also ranked as the second most common secondary source. A small proportion of individuals reported receiving money from other sources, as well (See Table 6).

Consumer Demographics

Thirty-one out of thirty-eight respondents indicated that they do work with individuals having mental retardation or developmental disabilities. In addition, on average, 73.7% of the population served has MR/DD including diagnoses such as mild, moderate, and severe MR, PDD, Dually Diagnosed (MH/MR), multihandicapped, LD/ADD.

When looking at the breakdown in the diagnoses of consumers, the primary populations were individuals who were physically or multiply handicapped. Five individuals indicated that they worked with diagnoses other than the options available. The next most common diagnoses were mild and severe MR as well as LD/ADD. The least common populations served were individuals having moderate MR, PDD, or dual diagnoses (MR/MH) (See Table 7).

TABLE 6. Primary Source of Facility Funding

Type of Funding	Frequency	Percent
State MH	2	6.3%
State MR	6	18.8%
Private-not for profit	3	9.4%
Private-for profit	2	6.3%
Medicaid	8	25.0%
Medicare	2	6.3%
State Vocational/Educational Office (VESID)	2	6.3%
Government Funding/Taxes	3	9.4%
Other	4	12.5%

n= 32

TABLE 7. Primary Population Served

Diagnosis	Frequency	Percent served
Mild MR	4	11.11%
Moderate MR	2	5.56%
Severe MR	4	11.11%
Physical Disability	6	16.67%
Pervasive Developmental Delays (PDD)	2	5.56%
Multihandicapped	6	16.67%
Dually Diagnosed (MH/MR)	2	5.56%
LD/ADD	4	11.11%
All Levels of MR	1	2.77%
Other	5	13.88%

n= 36

Living Arrangements of Consumers

The respondents were asked where the clients they served resided. More than one option was selected by most therapists. Most of their consumers live at home with their families (n= 10). Foster care provided the second most common setting (n= 5), and group homes were the third most common residential setting (n= 5). When considering the age ranges of the consumers, 70% for those under age thirteen reported that their clientele live at home with families. The other 30% who lived at home were between the ages of thirteen to forty. Eighty percent of the OT's serve individuals living in foster care are below the age of thirteen, and the other twenty percent are between twenty-one to forty years of age. In contrast, only 40% serve people under the age of thirteen who live in group homes, whereas 60% of the therapists report group home clients who were above the age of twenty-one (See Table 8).

A comparison of diagnosis and living arrangement was also done. No real pattern, such as whether one diagnosis was found to reside in a particular setting more often, was found to exist in this data.

Participant Role

Of the thirty-seven participants, only thirteen (34.2%) work in the transitioning of their consumers, whereas twenty-four (63.2%) stated that they do not work in this area. Two individuals filled out the second portion of the survey that related only to transitioning, however, their responses were not included because they did not report working in the transitioning of their consumers. For this reason, responses for the remaining questions were available only from a group of thirteen.

Eleven therapists reported having more than one role in transitioning.

When therapists doing transitioning were asked the following question: "What do you feel is your primary role when working with consumers?" the majority of participants (77%) stated either evaluation or individual work. Only 15.4% use group work as a primary way of treating consumers, and 15.4% also work on a consultative basis. A small number (7.6%) of respondents indicated other methods used (See Table 9).

Assessments Used

The question "Do you use any standardized assessments when evaluating consumers?" was posed in the survey to therapists who work in transitioning. A total of seven out of thirteen therapists (53.8%) stated that they did use standardized assessments. Some of the assessments that were listed as being used include: Kohlman Evaluation of Living Skills, Lowenstein Occupational Therapy Cognitive Assessment, McCarron-Dial Work Evaluation System, Developmental Test of Visual Motor Integration, Motor Free Visual Perceptual Test, Peabody, Wide Range Achievement Test, Oregon Project Skills Inventory for Blind Children, Hawaii Early Learning Profile, Sensory Integration Inventory, and Bruininks-Oseretsky Test of Motor Proficiency.

Transportation Arrangements of Consumers

When asked how their transitioning consumers travel to their facility, the majority of participants (76.9%) stated that their consumers use special buses to get to the facility. Most agencies are reached by several different transportation options. A total of 61.5% of respondents reported that consumers also use private transportation. Similarly, 61.5% respondents indicated that consumers get to the

facility via family or friends, and the same number use special vans. Five participants (38.5%) stated that their consumers use public buses, and the same percentage get to the facility by walking. Taxis are used to get to 30.8% of the facilities served. Bicycling to the facility was reported by 23.1% of the therapists as a way for consumers to reach the facility. The smallest percentage reported was for school buses (15.4%) or the train or metro (15.4%) (See Table 10).

Skills Taught in Transitional Programming

Based on the occupational performance list of twenty-eight different skills, eleven skills came to the forefront as those taught in transitional programming for mentally retarded individuals. This list represent the relative frequency of the elements reported with number one, feeding or eating selected most frequently by, number two, dressing next most common, etc. (See Table 11). The order of frequency was:

1. Feeding or Eating
2. Dressing
3. Oral Hygiene
4. Play or Leisure Exploration
5. Self-control
6. Safety
7. Grooming
8. Toilet Hygiene
9. Functional Communication
10. Coping Skills
11. Work Performance

TABLE 8. Primary Consumer Setting and Age Ranges

Age Ranges	Living at Home with Family	Living in Foster Care	Living in a Group Home
0-5	1 (2.7%)	1 (2.7%)	0 (0%)
6-12	6 (16.2%)	3 (8.1%)	2 (5.4%)
13-20	0 (0%)	0 (0%)	0 (0%)
21-40	1 (2.7%)	1 (2.7%)	2 (5.4%)
41-64	2 (5.4%)	0 (0%)	1 (2.7%)
65 and above	0 (0%)	0 (0%)	0 (0%)

n=37

TABLE 9. Primary Role of Therapists when Working With Consumers

Role	Frequency	Percent
Consult	2	15.4%
Evaluation	4	30.8%
Group Work	2	15.4%
Individual Work	4	30.8%
Other	1	7.6%
Counseling	0	0%
Screening	0	0%

n= 13

The importance of program elements presented was also assessed. A Likert scale of one to ten, where one meant that the skill was absolutely necessary for transitional programming, and ten meant that the skill was not necessary to transitional programming, was used to discover the perceived importance of these skills when transitioning consumers. For purposes of analysis, it was assumed those skills given a mean rating of one to four were considered necessary, a score of five was indifferent, and scores falling from six to ten were considered not necessary. A total of five skills, vocational exploration, care of others, sexual expression, yard maintenance, and volunteer participation fell in the range of being considered not necessary. The majority of the participants (See Table 12 and Figure 1) deemed all other skills listed as necessary. Three skills fell in the 1.0 to 1.9 range, nine in the 2.0 to 2.9 range, and ten between 3.0 and 5.0.

Rural Versus Urban Therapists

Since Arnold and Seekins (1998) found differences between rural and urban vocational counselors, results of this study were analyzed by rural versus urban. It was expected that there would be significant differences between rural and urban therapists based on the differences found the similar study done by Arnold and Seekins, (1998). These differences were expected to be in the areas of availability and access to transportation, housing, employment, and advocacy groups for the participant's client population. For most areas, no differences were found. One difference found was that in urban areas, forty percent of urban therapists versus one hundred percent of rural therapists who stated disagreement with the statement, "Public transportation is available and responsive to consumers."

TABLE 10. Types of Transportation Used by Consumers

Transportation	Frequency	Percent
Special Buses	10	76.9%
Special Vans	8	61.5%
Private Transportation	8	61.5%
Family/Friends	8	61.5%
Public Buses	5	38.5%
Walk	5	38.5%
Taxis	4	30.8%
Bicycle	3	23.1%
School Buses	2	15.4%
Train/Metro	2	15.4%

n= 13

TABLE 11. Are any of the following skills taught in your programming?

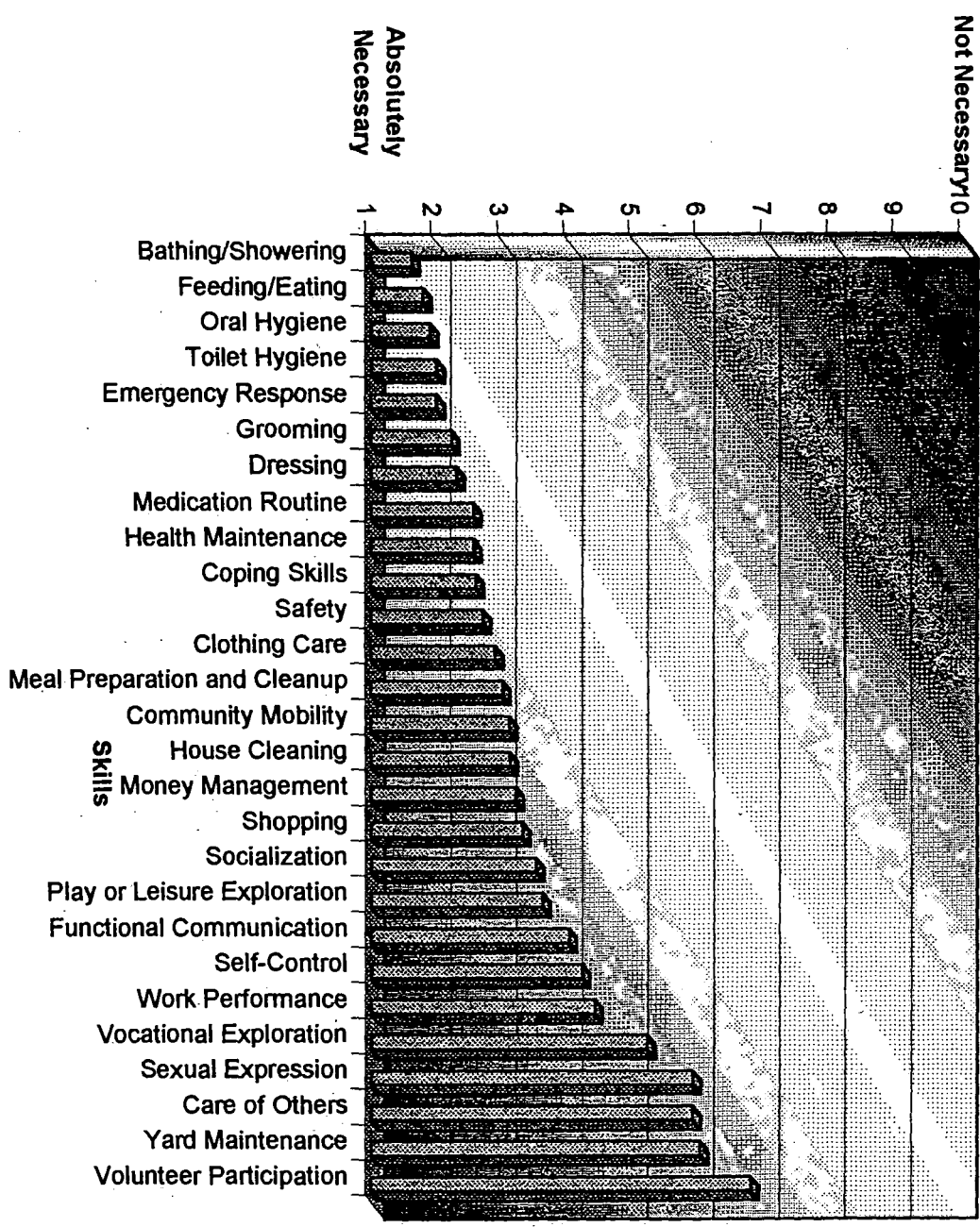
<i>Skill</i>	<i>Yes</i>	<i>No</i>
Feeding or Eating	13 (100%)	0 (0%)
Dressing	12 (92.3%)	1 (7.7%)
Oral Hygiene	12 (92.3%)	1 (7.7%)
Socialization	12 (92.3%)	2 (7.7%)
Play or Leisure Exploration	12 (92.3%)	2 (7.7%)
Self-control	12 (92.3%)	2 (7.7%)
Safety	11 (78.6%)	3 (21.4%)
Grooming	10 (76.9%)	3 (23.1%)
Toilet Hygiene	10 (76.9%)	3 (23.1%)
Functional Communication	10 (76.9%)	3 (23.1%)
Coping Skills	10 (71.4%)	4 (28.6%)
Work Performance	9 (75%)	3 (25%)
Community Mobility	9 (69.2%)	4 (30.8%)
Meal Preparation and Clean-up	9 (62.2%)	4 (30.8%)
Time Management	9 (62.2%)	4 (30.8%)
Shopping	8 (61.5%)	5 (38.5%)
Money Management	8 (61.5%)	5 (38.5%)
Health Maintenance	7 (53.8%)	6 (46.2%)
Emergency Response	7 (53.8%)	6 (46.2%)
Vocational Exploration	7 (53.8%)	6 (46.2%)
Clothing Care	6 (46.2%)	7 (53.8%)
House Cleaning	5 (38.5%)	8 (61.5%)
Volunteer Participation	5 (38.5%)	8 (61.5%)
Bathing/ Showering	4 (30.8%)	9 (69.2%)
Medication Routine	2 (15.4%)	11 (84.6%)
Sexual Expression	2 (15.4%)	11 (84.6%)
Care of Others	2 (15.4%)	11 (84.6%)
Yard Maintenance	1 (7.7%)	12 (92.3%)

TABLE 12. Perceived Importance of Skills on a Likert Scale of one (absolutely necessary) to ten (not necessary)

	Mean	n	Range	Standard Deviation
Bathing/Showering	1.6250	8	1.0-5.0	+ 1.4079
Feeding/Eating	1.8000	10	1.0-8.0	+ 2.2010
Oral Hygiene	1.9000	10	1.0-4.0	+ 0.8756
Toilet Hygiene	2.0000	10	1.0-5.0	+ 1.6330
Emergency Response	2.0000	9	1.0-4.0	+ 1.2247
Grooming	2.2222	9	1.0-5.0	+ 1.3017
Dressing	2.3000	10	1.0-9.0	+ 2.6687
Medication Routine	2.5556	9	1.0-5.0	+ 1.7401
Health Maintenance	2.5556	9	1.0-5.0	+ 1.3333
Coping Skills	2.6000	10	1.0-6.0	+ 1.7764
Safety	2.7000	10	1.0-10.0	+ 3.1640
Clothing Care	2.8889	9	1.0-7.0	+ 2.0276
Meal Preparation and Cleanup	3.0000	10	1.0-7.0	+ 1.9437
Community Mobility	3.1000	10	1.0-5.0	+ 1.6633
House Cleaning	3.1111	9	1.0-5.0	+ 1.4530
Money Management	3.2000	10	1.0-8.0	+ 2.0440
Shopping	3.3000	10	1.0-5.0	+ 1.5670
Socialization	3.5000	10	1.0-9.0	+ 2.5495
Play or Leisure Exploration	3.6000	10	1.0-9.0	+ 2.2211
Functional Communication	4.0000	10	1.0-10.0	+ 3.5277
Self-Control	4.2000	10	1.0-10.0	+ 3.0840
Work Performance	4.4000	10	1.0-10.0	+ 2.7568
Vocational Exploration	5.2000	10	1.0-10.0	+ 3.3267
Sexual Expression	5.8889	9	1.0-10.0 *	+ 5.8618
Care of Others	5.8889	9	1.0-10.0	+ 3.4440
Yard Maintenance	6.0000	9	1.0-10.0	+ 3.7081
Volunteer Participation	6.7778	9	1.0-10.0	+ 3.1136

***One individual marked sexual expression as greater than 10.0 (20.0), this was recorded as 10.0, the highest rating provided.**

Figure 1
Perceived Importance of Skills



A slight difference was also found in perceived availability of employment options for consumers. Therapists working in urban settings stated a 60% feeling of disagreement with the statement, "Locally, there are a variety of employment options." In comparison, rural therapists stated a 100% agreement with the same statement.

DISCUSSION

Discussion of Survey Response

The results of this survey must be considered in light of the limited number and rate of respondents. The results, then, can only suggest issues for further study, rather than provide answers to our research questions. The majority of individuals who responded to the survey are currently working with children between the ages of zero to twelve, and do not work in the transitioning of these children. To increase the response to the transitional living survey, it would have been necessary to sample a much larger population (greater than 150) within the DDSIS. Of the thirty-eight respondents, thirteen (34%) stated that they work in transition services.

Transition programming is mandated for individuals with handicaps from the age of fourteen to twenty-two. Since most therapists surveyed work with younger children, they may not generally be involved with transitioning. It appears from the survey that most therapists in New York State who work with individuals having developmental disabilities are seeing younger children, probably in the schools, and that perhaps, there is still a potential gap in the services provided by school based occupational therapists in New York State, with few working in secondary programs where vocational and community living skills are appropriate programming options.

Use of Theoretical Models

Among all the therapists, particularly those working with consumers under the age of twenty-one, a developmental approach is most common when

providing therapy. This has some important implications. Traditionally, therapists working with individuals with developmental disabilities have used a developmental approach. This may be appropriate for younger children who are still developing prerequisite skills needed to perform more complex tasks and whose neurological systems are still developing. For some individuals, however, this is not appropriate. As a child gets older, it becomes more important to teach a functional skill that will be needed for survival, rather than continuing to work on a precursor skill that may no longer be age-appropriate. Use of developmental models alone with older children, adolescents, and adults is probably not sufficient to enable these individuals to reach their potential for independent work and living.

The developmental model for young children is well defined. However, as disabled individuals age, the process of development is not as clear or consistent. This could be one of the reasons why some shift in the use of OT theory was noted at the client age range of twenty-one and above. At this age range, therapists appear to shift from the developmental approach to other approaches, such as vocational rehabilitation, cognitive, behavioral, and OB and MOHO. These models tend to focus on specific deficit remediation or, to focus on performance of life roles and skills. This is a most appropriate shift in practice models.

Team Members

Occupational therapy personnel work with many different professionals to serve their DD consumers. Commonly noted team members were physical

therapy, speech therapy, psychologists, social work, and educators. These teams are common within school systems and institutions. An interesting finding in the study was that therapeutic recreation was only represented on the team 5.4% of the time. One reason to explain this may be that most respondents work with young children, possibly in the context of schools. In the school system where younger individuals with developmental disabilities are likely to be seen, recreational therapy is rare. Recreation-like activities take place within classes such as art, music, and gym. Hence, while DD children may engage in recreational activities, they may not take place as therapy, or within school hours. It is possible that those participants who listed therapeutic recreation as members of their team work with an older population and are employed in hospitals, or community agencies.

Surprisingly, only thirty out of thirty-seven individuals (81.1%) listed members of their own profession, OT's, as part of the team. There are two possible explanations for this. The most likely reason is that since this survey was completed by individuals working in the field of occupational therapy, they saw no reason to list themselves and assumed that this was a given. Another possible reason could be that occupational therapists are not represented as regular members of the team in many cases, or that the respondent is the only OT on the team.

Occupational Therapist's Role When Working with Clients in Transition

The majority of these OT's say their role when working with consumers is evaluation and individual work. According to Brollier (1994), "occupational

therapists in transition programs can address [work, education, independent living, and community participation] by providing direct or indirect therapy, consultation, and monitoring while offering services in school and community environments" (Brolhier et. al., 1994, p. 350). Most of these therapists are continuing with primarily traditional models of service delivery rather than utilizing the potential opportunities presented by other types of service delivery. Roles for occupational therapy in transition programming are multifaceted. These practitioners may be underutilizing more indirect models such as consultation and monitoring which may be more appropriate in transitioning and allow OT's to maximize the efficiency and economy of service delivery. Occupational therapists not only teach functional daily living skills, but they also help structure the environment as well as modify student's skills to meet the environmental demands (Brolhier et. al., 1994). These indirect services may be the best use of OT expertise in transitioning.

One possible reason for the continued use of traditional individual treatment may be because OTs have tried other roles when working with consumers, yet have found the most success when working one-on-one with consumers. Therapists may also be selecting the roles with which they are most familiar and comfortable, or agencies may be unaware of other ways for OT professionals to provide care. These occupational therapists may also be seeing only the most needy individuals served by the agency and, therefore, programming individually may be mandated by special client needs. It is certainly possible that occupational therapists need to promote the various

treatment options, and it may be necessary for occupational therapists to sell their role in the transitioning process in order to adequately provide for the consumer's needs. Successful marketing of indirect services could result in a broader scope of more effective services.

Skills Taught and their Perceived Importance

Based on the literature review (Sale et. al., 1998), it was expected that community mobility, vocational exploration, money management, coping skills, medication routine, emergency response, play or leisure exploration, socialization, clothing care, and meal preparation and clean-up would come to the forefront when providing transitional living skills. These are primarily IADL and community living skills. The survey respondents answered this question quite differently. They included many more basic activity of daily living skills and fewer IADL's and community skills.

Only two skills that were expected to be important in transitional programming matched those reported to be used by therapists working in transitioning in New York State. The perceived importance of items on the survey incorporated more basic activity of daily living skills, and fewer high-level community skills than suggested by the literature. This may be because of the age group served or OT roles. Another reason for differences may be that in transition programming OT's role may be to work on 'earlier skills' while other professionals address the actual transitioning skills.

Within the eleven skills reported as being perceived to be important for transitional programming: bathing/showering, feeding/eating, oral hygiene, toilet

hygiene, grooming, dressing, emergency response, medication routine, health maintenance, safety, and coping skills were all recognized. All but two of these skills were also reported within the top eleven skills actually being taught in transition programming. The two skills perceived as important but were not among the top eleven used included emergency response and medication routine. These skills are considered to be high-level vocational-related skills. Although they are not taught as frequently by therapists working in transitioning, they are perceived to be of importance, and the respondents felt that they should be taught as prerequisites for independent living. It is possible that emergency response and medication routine are skills that are taught by other individuals working with the consumer, such as nursing, and they are therefore not taught by occupational therapists in their programming or it may be that this program need is being overlooked on some transition teams.

Rural-based and Urban-based Therapists

A study done in 1998 by Arnold & Seekins found that there were significant differences noted in the experiences of rural and urban vocational counselors working on transitioning. For this reason, a comparison was done on the perceptions of both rural and urban therapists in New York State. The results of this study indicate that rural and urban therapists hold similarly positive and negative ideas about the availability of transportation, employment, housing, and self-advocacy groups for the consumers that they serve. Unlike the study done by Arnold & Seekins, there were only minimal differences noted by program location in this study. Slight differences were found in the availability of

transportation which urban therapists indicated was slightly more available, and in the perceived availability of employment, where rural therapists reported higher levels of employment opportunity than did urban therapists. It seems logical that more transportation would be accessible in an urban area due to the larger number of trains, metros, taxis, and various other forms of transportation available in cities. In reference to availability of jobs, it would also make sense that urban areas would have a greater variety of employment opportunities. However, there may be more competition for jobs in an urban setting. This could negatively affect the availability of employment. In this study, rural programs were reported to have better job opportunities for their consumers. As in the Arnold & Seekins (1998) study, no difference was found regarding the theories used when treating clients, primarily developmental, or the necessity of client and family participation in treatment and goal setting in urban versus rural settings (Arnold & Seekins, 1998).

In summary, there were some interesting findings in this study. A majority of occupational therapists working with younger children do not report working in transitioning. Therapist work patterns still focus on direct service and assessment. Work patterns also focus on teaching of basic ADL's instead of higher-level skills. In contrast, they appear to recognize the importance of more mature transitioning skills such as IADL's and self-management of behavior. It may be that OT's are underutilized in transition teams and for community living skills, or they may be focusing on filling a unique role on transition teams.

Directions for Future Research

Further research on a larger scale is needed to find out why OT's are still working in traditional roles instead of branching out into other areas of service delivery. Based on the low return rate (25%) of surveys, even given an incentive to participate and a reminder letter, this researcher feels that using AOTA's DDSIS may not have been the most appropriate list to use considering the content of the survey. Two different approaches might have been taken. One would involve contacting facilities that provide transitioning services, and then obtain a list of occupational therapists or assistants who work within the facility. Another way to get a better response rate could be to use a different AOTA special interest section such as school-based, work programs, or a combination of both. These special interest sections would also have limitations however. Each of these options can be expected to identify only a small portion of the therapist groups specifically working with the population of interest. Therefore, the best way to get to the transitional population may be via a customized listing of therapists who work with individuals in the age range of fourteen to twenty-two, and this may not even be possible. Further research then may require a larger two-stage survey with the survey mailed only to qualified respondents in the second round. Due to the low response rate, this study was not able to determine specific reasons or patterns. Further research on a much larger scale is needed to identify elements of program and OT effectiveness when providing transitional services to individuals with MR or DD.

SUMMARY

This study has examined the views and perceptions of occupational therapy personnel working with developmentally disabled individuals by reviewing their current practice, theory, setting, consumer population, and by gathering data through the use of a survey questionnaire that assessed their perceptions on the process of transitioning of the consumer.

The research questions of this study were answered in regard to how involved occupational therapists are in the transitioning process, theories being used and the age ranges with which they are used, services that are provided and are felt to be needed, perceptions of rural versus urban therapists in relation to availability, the occupational therapist's roles, and team members who work with the consumer. However, the small sample response limits the generalizability of the results

Based on this study, occupational therapists appear to play a limited role in the transitioning of their consumers. Most work with younger children. There is a demand for knowledgeable professionals in this area, and the potential exists to greatly increase the role that occupational therapists play in this area. The finding that sixty-six percent of the participants in this study reported that they do not work in transitioning highlighted the need for occupational therapists to look further into what can be done in this area. Implications of this study are that occupational therapy personnel working with a younger age group of children focus less on transitioning, and more on the development of age-appropriate skills of younger childhood.

Although not determined by this research study, it is possible that many of the therapists surveyed are indirectly working in the transitioning of consumers, however, they have not attached that name to what they are doing. In this regard, it is important to define what transitioning means to the profession of occupational therapy. By increasing awareness of the role that occupational therapists can play in the transitioning of consumers at any age, the familiarity with the transitioning process would be greatly enhanced.

During the course of this study, the current perceptions and practice of occupational therapy personnel in regards to transitioning have been examined, as well as the factors that contribute to these. There were some differences in the skills that were being taught in transitioning (primarily ADL's) and the perceived importance of these skills. There were minimal differences noted in the perceptions and experiences of OT's working in rural and urban areas. Most of the factors, such as age, theory, and roles, directly affect transitioning and thus the growth of the profession. The factors highlighted in this study can be directly influenced by occupational therapy professionals who can bring about an increased awareness of the role that can be played in transitioning. By increasing this awareness, a number of opportunities for occupational therapy professionals in non-traditional settings could arise, and this would greatly benefit the profession.

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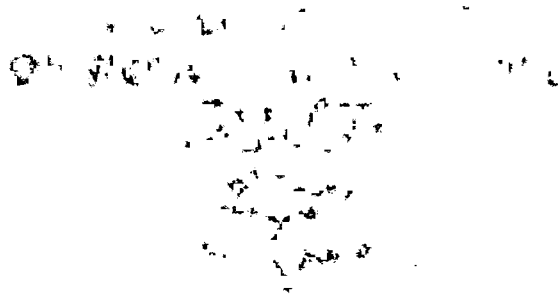
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Transitional Living- Appendix A

Andrea Fadel

Ithaca College



Transitional Living Survey:

A. Respondent Information

1. What is your current job title? _____
2. What is your education level?

<input type="checkbox"/> High School Graduate	<input type="checkbox"/> Associates Degree	<input type="checkbox"/> Masters Degree
<input type="checkbox"/> Some college	<input type="checkbox"/> Bachelors Degree	<input type="checkbox"/> Doctorate
3. How long have you been practicing in this field? _____
4. How long have you been practicing in this facility? _____
5. Do you use any of the following theories when working with consumers? Check all that apply.

<input type="checkbox"/> Vocational Rehabilitation	<input type="checkbox"/> Behavioral	<input type="checkbox"/> Cognitive
<input type="checkbox"/> Psychodynamic	<input type="checkbox"/> Occupational Science	<input type="checkbox"/> Developmental
<input type="checkbox"/> Other _____		

B. Facility Information

6. How long has your facility been established?

<input type="checkbox"/> One year or less	<input type="checkbox"/> 2 to 5 years	<input type="checkbox"/> 16 to 20 years
<input type="checkbox"/> 6 to 10 years	<input type="checkbox"/> 11 to 15 years	<input type="checkbox"/> Greater than 20 years
7. What type of setting is your facility located in?

<input type="checkbox"/> rural	<input type="checkbox"/> small town	<input type="checkbox"/> large town	<input type="checkbox"/> suburban	<input type="checkbox"/> urban	<input type="checkbox"/> Other _____
--------------------------------	-------------------------------------	-------------------------------------	-----------------------------------	--------------------------------	--------------------------------------
8. How is your facility funded?

<input type="checkbox"/> State MH	<input type="checkbox"/> State MR	<input type="checkbox"/> Voluntary	<input type="checkbox"/> Private-for profit	<input type="checkbox"/> Other _____
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C. Client Population

9. What client population does your facility serve? Check all that apply.

<input type="checkbox"/> Mild MR	<input type="checkbox"/> Moderate MR	<input type="checkbox"/> Severe MR	<input type="checkbox"/> Psychiatric	<input type="checkbox"/> Physical Disability
<input type="checkbox"/> Pervasive Developmental Delays (PDD)	<input type="checkbox"/> Multihandicapped	<input type="checkbox"/> Dually Diagnosed		
<input type="checkbox"/> Other _____				
10. What age ranges does your facility serve? _____

D. Community Resources

11. How do your consumers get from your facility to special programs and activities? Check all that apply.

<input type="checkbox"/> public buses	<input type="checkbox"/> special buses	<input type="checkbox"/> walk
<input type="checkbox"/> special vans	<input type="checkbox"/> train/ metro	<input type="checkbox"/> taxis
<input type="checkbox"/> bicycle	<input type="checkbox"/> private transportation	<input type="checkbox"/> other _____

12. What types of housing options do you recommend for your consumers? Check all that apply.

- Group Homes Independent Living Centers Apartments
 Transitional Living Apartments Private Homes Supported Living/ Live-in help
 Other _____

13. Would you say that you **strongly agree**, **agree**, are **neutral**, **disagree**, or **strongly disagree** with the following statements?

	<u>SA</u>	<u>A</u>	<u>N</u>	<u>D</u>	<u>SD</u>
a. Public Transportation is accessible and responsive to consumers.	1	2	3	4	5
b. Consumers have transportation.	1	2	3	4	5
c. Locally, there are a variety of employment options.	1	2	3	4	5
d. Local employers hire individuals with disabilities.	1	2	3	4	5
e. Job service, coaches are available in your area.	1	2	3	4	5
f. You have time to provide counseling that helps consumers adjust to their disability.	1	2	3	4	5
g. Your consumers have access to an independent living center.	1	2	3	4	5
h. Your office has enough staff and other resources.	1	2	3	4	5
i. Your consumers have adequate access to assistive technology.	1	2	3	4	5
j. You have time to develop an initial rapport with your consumers.	1	2	3	4	5

E. Programming

14. Do you serve consumers in any of the following ways? Check all that apply.

- consult evaluation group work individual work counseling Other _____

a. From the above choices, what do you feel is your primary role when working with consumers? _____

15. Who are the members of your team who work with the consumer? _____



16. The following question consists of two parts.

a. In your programming, do you teach any of the following skills? Check **yes** or **no**.

b. To the left of the skill, please rate each skill on a level of 1 to 10, where 1 means it is absolutely necessary to teach the skill for independent living and 10 means it is not necessary to teach the skill for independent living.

	Yes	No
_____ a. grooming	<input type="checkbox"/>	<input type="checkbox"/>
_____ b. oral hygiene	<input type="checkbox"/>	<input type="checkbox"/>
_____ c. bathing/ showering	<input type="checkbox"/>	<input type="checkbox"/>
_____ d. toilet hygiene	<input type="checkbox"/>	<input type="checkbox"/>
_____ e. dressing	<input type="checkbox"/>	<input type="checkbox"/>
_____ f. feeding or eating	<input type="checkbox"/>	<input type="checkbox"/>
_____ g. medication routine	<input type="checkbox"/>	<input type="checkbox"/>
_____ h. health maintenance	<input type="checkbox"/>	<input type="checkbox"/>
_____ I. socialization	<input type="checkbox"/>	<input type="checkbox"/>
_____ j. functional communication	<input type="checkbox"/>	<input type="checkbox"/>
_____ k. community mobility	<input type="checkbox"/>	<input type="checkbox"/>
_____ l. emergency response	<input type="checkbox"/>	<input type="checkbox"/>
_____ m. sexual expression	<input type="checkbox"/>	<input type="checkbox"/>
_____ n. clothing care	<input type="checkbox"/>	<input type="checkbox"/>
_____ o. house cleaning	<input type="checkbox"/>	<input type="checkbox"/>
_____ p. meal preparation and cleanup	<input type="checkbox"/>	<input type="checkbox"/>
_____ q. shopping	<input type="checkbox"/>	<input type="checkbox"/>
_____ r. money management	<input type="checkbox"/>	<input type="checkbox"/>
_____ s. yard maintenance	<input type="checkbox"/>	<input type="checkbox"/>
_____ t. care of others	<input type="checkbox"/>	<input type="checkbox"/>
_____ u. vocational exploration	<input type="checkbox"/>	<input type="checkbox"/>
_____ v. volunteer participation	<input type="checkbox"/>	<input type="checkbox"/>
_____ w. play or leisure exploration	<input type="checkbox"/>	<input type="checkbox"/>
_____ x. coping skills	<input type="checkbox"/>	<input type="checkbox"/>
_____ y. time management	<input type="checkbox"/>	<input type="checkbox"/>
_____ z. self-control	<input type="checkbox"/>	<input type="checkbox"/>

17. To what extent do you agree with the following statements? Would you say you **(1) strongly agree**, **(2) somewhat agree**, are **(3) neutral**, **(4) somewhat disagree**, or **(5) strongly disagree**?

a. Transition plans should be written according to the individual consumer.	1	2	3	4	5
b. Standardized assessments should be used to identify goals and objectives.	1	2	3	4	5
c. Parents should actively participate in transition planning meetings	1	2	3	4	5
d. Consumers should actively participate in transition planning meetings.	1	2	3	4	5
e. Parents and family members should not participate in implementation of transition goals and objectives at home.	1	2	3	4	5

To what extent do you agree with the following statements? Would you say you **(1) strongly agree, (2) somewhat agree, are (3) neutral, (4) somewhat disagree, or (5) strongly disagree?**

f. Family preferences should be reflected in transition goals and objectives.	1	2	3	4	5
g. Consumer preferences should be reflected in transition goals and objectives.	1	2	3	4	5
h. Group homes are locally available.	1	2	3	4	5
I. Specialized transportation services are locally available	1	2	3	4	5
j. Self-advocacy groups are locally available.	1	2	3	4	5
k. Independent Living Centers are locally available.	1	2	3	4	5
l. Consumers receiving transition services should have access to support groups.	1	2	3	4	5

Running Head: TRANSITIONAL LIVING- APPENDIX B

Transitional Living- Appendix B

Andrea Fadel

Ithaca College

ITHACA

Office of the Provost and
Vice President for
Academic Affairs

DATE: November 30, 1999

TO: Andrea Fadel
222 North A
Ithaca, NY 1

FROM: Garry L. Bro Provost
All-College Human Subjects Research

SUBJECT: Transitional Living Study

The All-College Review Board for Human Subjects Research (HSR) has received your request for expedited review of the above named proposal. The Board has completed its review and has made the following stipulations:

A raffle is illegal in the state of New York and, therefore, the word *raffle* throughout the proposal should be revised to either *drawing* or *door prize*.

The Recruitment Statement should include a statement that subjects must be at least 18 years of age or older to participate.

The last sentence under the heading *What will this Entail?* on the Informed Consent Form should be revised to read: *As a thank you, if you return the survey, you will be eligible for a \$25 savings bond.*

The sentence under the heading *Withdrawal from the Study* should be revised to read: *You are free to answer only those questions that you choose or to stop answering questions altogether.*

The Board also had the following consultative comment:

Grammatical or writing errors were noted throughout the proposal. The Board suggests careful editing prior to sharing this document more widely.

Please submit one copy of the revised pages to the Office of the Provost and Vice President for Academic Affairs for final review.

/w

c: Catherine Gordon, Faculty Advisor

ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCH

COVER PAGE

Investigators: Andrea Fadel

Department: Occupational Therapy

Telephone: 274-1975 275-3059
(Campus) (Home)


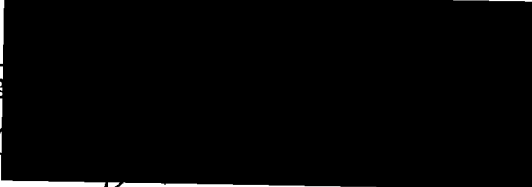
Project Title: Transitional Living Study

Abstract: (Limit to space provided)

see attached

Proposed Date of Implementation: January 10, 2000

Andrea Fadel and Dr. Catherine Gordon
Print or Type Name of Principal Investigator and Faculty Advisor

 
Signature (Use blue ink) Principal Investigator

ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCH

CHECKLIST

Project Title: Transitional Living Study
Investigator(s): Andrea Fadel

Investigator Use	HSR Use Only	Items for Checklist
<u>X</u>	<u> </u>	1. General information
<u>X</u>	<u> </u>	2. Related experience of investigator(s)
<u>X</u>	<u> </u>	3. Benefits of the study
<u>X</u>	<u> </u>	4. Description of subjects
<u>X</u>	<u> </u>	5. Description of subject participation
<u>X</u>	<u> </u>	6. Description of ethical issues/risks of participation
<u>X</u>	<u> </u>	7. Description of recruitment of subjects
<u>X</u>	<u> </u>	8. Description of how anonymity/confidentiality will be maintained.
<u>X</u>	<u> </u>	9. Debriefing statement
<u>X</u>	<u> </u>	10. Compensatory follow-up
<u>X</u>	<u> </u>	11. Appendix A - Recruitment Statement
<u>X</u>	<u> </u>	12. Appendix B - Informed Consent Form (or tear-off Cover Page for anonymous paper and pen/pencil surveys)
<u>NA</u>	<u> </u>	13. Appendix C - Debriefing Statement
<u>X</u>	<u> </u>	14. Appendix D - Survey Instruments
<u>NA</u>	<u> </u>	15. Appendix E - Glossary to questionnaires, etc.

Items 1-8, 11, and 12 must be addressed and included in the proposal. Items 9, 10, and 13-15 should also be checked if they are appropriate - indicate "NA" if not appropriate. This should be the second page of the proposal.

Abstract:

There is currently very little research on community programming for individuals with mental retardation. The purpose of this study is to look at transitional practices in New York State and to discover what elements are most commonly used to teach transitional living skills. It will also look at whether these elements are perceived to be successful or unsuccessful by these occupational therapists. I propose to do this through a paper and pencil mail survey. A survey was developed for occupational therapists, and it looks at the facility as well as the primary skills that are taught to their consumer population. On January 10, 2000, 120 surveys will be sent out to randomly assigned facilities in New York State. Follow up letters will be sent out ten days later, and the deadline to return surveys will be February 20, 2000. All usable surveys will then be analyzed, and a summary of results will be sent to facilities that wish to receive them.

1. General Information about the Study

a) Funding

This is essentially an unfunded thesis project. Costs for paper, duplication of surveys, stamps, and envelopes will cost approximately \$100 and will be covered by a graduate study grant to the Occupational Therapy Department and student funds. A \$25 savings bond drawing will be covered in full by myself.

b) Location

The survey packets will be assembled at Ithaca College. They will then be post marked and sent from Ithaca College. The survey will be completed by therapists at their place of work. It will then be returned to Ithaca College Occupational Therapy Department attn. A. Fadel. The address list that will be used for follow up reasons will be kept separately in Dr. Gordon's office.

c) Time period

Informed consent letters and surveys will be mailed out together by January 10, 2000. A reminder card will be sent out on January 20, 2000. The requested return date for completed surveys will be by February 15, 2000. Analysis will follow the return of surveys, and will tentatively be completed by March 31, 2000.

2. Related Experience of the Researcher

I am currently a graduate student in occupational therapy. I have completed one fieldwork experience. I have also taken the following research courses as part of thesis work: Biostatistics 670-39000, Research Seminar 672-49500, and Research Methods 672-67000.

For this study, the supervising faculty is Dr. Catherine Y. Gordon. She is the Chair of the Occupational Therapy Department at Ithaca College. She is experienced in survey research and is also an experienced thesis supervisor

3. Benefits of the Study

Currently, there is little research on community programming with the mentally retarded population. Through this study insight will be gained into what skills are deemed necessary by occupational therapists working with mentally retarded individuals so they can be successful when transitioning from home to independent living. Participating facilities will receive a summary of the study when it is completed.

4. Description of the Subjects

a) How many subjects will be tested?

A total of 120 surveys will be sent out.

b) What are the salient characteristics of the subject population (i.e., age, gender, college, major, etc.)?

The population surveyed will include occupational therapy personnel who work in facilities where transitional living skills are taught to mentally retarded individuals. This study will only look at facilities in New York State. The survey respondents must be at least 18 years of age. Males or females may participate in the study. Names of facilities will be obtained through the Broome County Developmental Disability Service Office (DDSO) and the New York State DD Office.

5. Description of Subject Participation

A pencil and paper mail-in survey will be used to obtain the information for this study. The survey is four pages and takes approximately 20 minutes to complete. It will be pilot tested on 15 classmates and several faculty members. Some editorial changes are anticipated following the field test.

6. Ethical Issues - Description

a) Risks of Participation

Risks of participation are minimal. The potential risks of this study may include an increased level of work and possible stress on the participants to accurately fill out the information in the survey. Another risk is confidentiality, which will be assured by keeping a separate tear off sheet and making sure that no identifying information is anywhere on the survey itself.

b) Informed Consent

An informed consent form will be sent out with the survey. It is to be sent back with the survey, at which point it will be detached and kept separate from the survey. If a survey comes back without a signed informed consent form, the information on the survey will be deemed unusable. See attached informed consent form for further information.

7. Recruitment of Subjects

a) Recruitment Procedures

A list of facilities will be obtained from the Broome County Developmental Disability Service Office (DDSO) and the New York State DD office. From those lists, 120 facilities will be picked at random to receive the survey packet. It is estimated that

some of these agencies will not have occupational therapists or the surveys will not be routed to the proper department. For this reason, it is necessary to send out 20 copies beyond the original number of 100 participants.

b) Inducement to Participate

Participants who return the survey will be eligible for a \$25 savings bond drawing to be done at the end of the study. Each survey packet will have a ticket. If the survey and the ticket are returned, the ticket will be put into a box. Each ticket will have a number, and it will be separated from the surveys upon receipt. The tickets will be kept separate from the data. When all usable surveys have been received, one ticket will be drawn, and the number will be matched to the number on the address sheet. At that point, the person will be sent a savings bond for winning the drawing.

8. Confidentiality/ Anonymity of Responses

To ensure the confidentiality of the subject's response, a separate informed consent sheet will be attached to the mailed survey. The respondent will be made aware that no identifying information such as names, addresses, etc., should be anywhere on the actual survey. When the surveys are returned, the informed consent sheet and the ticket for the drawing will be separated from the surveys. The informed consent sheets will then be kept with the address sheet in Dr. Gordon's office. To assure confidentiality and for the reason of follow up, an address sheet will be kept separately from the returned surveys and will contain the address of the facility, the contact person, and an assigned ticket number. This sheet will only be used if it is necessary to send follow up surveys and after the drawing.

9. Debriefing

Final results of the study will be distributed based on whether the 'yes' or 'no' option was checked on the informed consent form. If 'yes' was indicated, results of the survey will be sent to the address that was given at the end of the form. A brief explanation of the results as well as a comparison of rural versus urban transitional living programs will be included, and will be mailed out following the conclusion of the study.

10. Compensatory Follow-up

Since there are no foreseeable negative physical or psychological outcomes due to participation in this study, compensatory treatment is not appropriate for this study.

Transitional Living

My name is Andrea Fadel and as part of my masters thesis in the Occupational Therapy program at Ithaca College, I am conducting a survey of transitional specialists to find out what is important when planning transitional living programs for mentally retarded individuals. This survey asks you to respond to questions about the demographics of the facility, and whether certain skills are necessary to teach to individuals who are planning on living in the community. You should feel free to leave any questions blank and/or to stop filling out this survey at any time.

When you have finished the survey please return the informed consent sheet, the survey, and the ticket stub in the attached self-addressed stamped envelope by February 20, 2000. The raffle will be drawn on February 25, 2000, and the winner will be called that day. You must be at least 18 years of age or older to participate. **DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY OR THE ATTACHED RETURN ENVELOPE.**

Thank you for helping me.

Andrea Fadel
Ithaca College Occupational Therapy Dept.
200 Smiddy Hall
Ithaca, NY 14850

INFORMED CONSENT: TRANSITIONAL LIVING STUDY

Purpose and Benefits of the Study:

The primary purpose of this study is to examine what key elements compose a successful transitional living program. Additionally, the study will look at whether these elements vary between rural and urban settings.

What will this entail?

You will be asked to fill out a pencil and paper mail-in survey that takes approximately 20 minutes to complete. The survey will include some personal questions such as the number of years you have practiced and your level of education. There will also be a number of questions about your facility. You are free to answer only those questions with which you feel comfortable, although any information you can give us is valuable. As a thank you, if you return the survey, you will be eligible for a \$50 savings bond.

For more information:

For any information before, during, or after the study please feel free to contact:

Occupational Therapy Department Attn. Andrea Fadel
Ithaca College
200 Smiddy Hall
Ithaca, NY 14850
(607) 274- 1975
email: afadel1@ic3.ithaca.edu

Withdrawal from the Study:

You are free to answer only those questions that you choose **or to stop answering questions altogether.**

Confidentiality of the Data:

All of the data from this study are confidential. That means your name will not be used in anyway and your responses will never be identified as coming from you.

Participant's Statement:

I have read the above and understand its contents. I acknowledge that I am 18 years of age or older. I agree to participate in the Transitional Living Study.

Print Name

Signature

Date

I would like a summary of the study results, check one. Yes No

If you checked yes, please give us the address where we should send the results:

Transitional Living Survey:

A. Respondent Information

1. What is your current job title? _____
2. What is your education level?

<input type="checkbox"/> High School Graduate	<input type="checkbox"/> Associates Degree	<input type="checkbox"/> Masters Degree
<input type="checkbox"/> Some college	<input type="checkbox"/> Bachelors Degree	<input type="checkbox"/> Doctorate
3. How long have you been practicing in this field? _____
4. How long have you been practicing in this facility? _____
5. Do you use any of the following theories when working with consumers? Check all that apply.

<input type="checkbox"/> Vocational Rehabilitation	<input type="checkbox"/> Behavioral	<input type="checkbox"/> Cognitive
<input type="checkbox"/> Psychodynamic	<input type="checkbox"/> Occupational Science	<input type="checkbox"/> Developmental
<input type="checkbox"/> Other _____		

B. Facility Information

6. How long has your facility been established?

<input type="checkbox"/> One year or less	<input type="checkbox"/> 2 to 5 years	<input type="checkbox"/> 16 to 20 years
<input type="checkbox"/> 6 to 10 years	<input type="checkbox"/> 11 to 15 years	<input type="checkbox"/> Greater than 20 years
7. What type of setting is your facility located in?

<input type="checkbox"/> rural	<input type="checkbox"/> small town	<input type="checkbox"/> large town	<input type="checkbox"/> suburban	<input type="checkbox"/> urban	<input type="checkbox"/> Other _____
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8. How is your facility funded?

<input type="checkbox"/> State MH	<input type="checkbox"/> State MR	<input type="checkbox"/> Voluntary	<input type="checkbox"/> Private-for profit	<input type="checkbox"/> Other _____
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C. Client Population

9. What client population does your facility serve? Check all that apply.

<input type="checkbox"/> Mild MR	<input type="checkbox"/> Moderate MR	<input type="checkbox"/> Severe MR	<input type="checkbox"/> Psychiatric	<input type="checkbox"/> Physical Disability
<input type="checkbox"/> Pervasive Developmental Delays (PDD)	<input type="checkbox"/> Multihandicapped	<input type="checkbox"/> Dually Diagnosed	<input type="checkbox"/> Other _____	
10. What age ranges does your facility serve? _____

D. Community Resources

11. How do your consumers get from your facility to special programs and activities? Check all that apply.

<input type="checkbox"/> public buses	<input type="checkbox"/> special buses	<input type="checkbox"/> walk
<input type="checkbox"/> special vans	<input type="checkbox"/> train/ metro	<input type="checkbox"/> taxis
<input type="checkbox"/> bicycle	<input type="checkbox"/> private transportation	<input type="checkbox"/> other _____

12. What types of housing options do you recommend for your consumers? Check all that apply.

- Group Homes Independent Living Centers Apartments
 Transitional Living Apartments Private Homes Supported Living/ Live-in help
 Other _____

13. Would you say that you strongly agree, agree, are neutral, disagree, or strongly disagree with the following statements?

	<u>SA</u>	<u>A</u>	<u>N</u>	<u>D</u>	<u>SD</u>
a. Public Transportation is accessible and responsive to consumers.	1	2	3	4	5
b. Consumers have transportation.	1	2	3	4	5
c. Locally, there are a variety of employment options.	1	2	3	4	5
d. Local employers hire individuals with disabilities.	1	2	3	4	5
e. Job service, coaches are available in your area.	1	2	3	4	5
f. You have time to provide counseling that helps consumers adjust to their disability.	1	2	3	4	5
g. Your consumers have access to an independent living center.	1	2	3	4	5
h. Your office has enough staff and other resources.	1	2	3	4	5
i. Your consumers have adequate access to assistive technology.	1	2	3	4	5
j. You have time to develop an initial rapport with your consumers.	1	2	3	4	5

E. Programming

14. Do you serve consumers in any of the following ways? Check all that apply.

- consult evaluation group work individual work counseling Other

a. From the above choices, what do you feel is your primary role when working with consumers? _____

15. Who are the members of your team who work with the consumer? _____

To what extent do you agree with the following statements? Would you say you (1) strongly agree, (2) somewhat agree, are (3) neutral, (4) somewhat disagree, or (5) strongly disagree?

- | | | | | | |
|--|---|---|---|---|---|
| f. Family preferences should be reflected in transition goals and objectives. | 1 | 2 | 3 | 4 | 5 |
| g. Consumer preferences should be reflected in transition goals and objectives. | 1 | 2 | 3 | 4 | 5 |
| h. Group homes are locally available. | 1 | 2 | 3 | 4 | 5 |
| I. Specialized transportation services are locally available | 1 | 2 | 3 | 4 | 5 |
| j. Self-advocacy groups are locally available. | 1 | 2 | 3 | 4 | 5 |
| k. Independent Living Centers are locally available. | 1 | 2 | 3 | 4 | 5 |
| l. Consumers receiving transition services should have access to support groups. | 1 | 2 | 3 | 4 | 5 |

Transitional Living- Appendix C

Andrea Fadel

Ithaca College

Drawing Information:

If you would like to be eligible for a \$50.00 savings bond drawing, please fill out the information below. This information will be separated from the survey upon receipt in order to maintain confidentiality of your answers. Thank you and good luck!

Name: _____

Street Address: _____

City/ State/ Zip Code: _____

Phone Number (Day): _____


Phone Number (Evening): _____

Transitional Living Survey

Dear

This is to remind you that the transitional living surveys were requested by March 10, 2000. I have not yet received your completed copy of this survey. If you have already returned the survey, thank you for doing so. If you have not, and you still wish to participate in the study, please fill out and return the survey by March 28, 2000. If you have any questions or need another copy of the survey, I can be reached at (607) 275-3059. I appreciate the time and effort you have put in to completing the survey. Thank you.

Sincerely,


Andrea Pader
Ithaca College Occupational Therapy Dept.
200 Smiddy Hall
Ithaca, NY 14850

Running Head: TRANSITIONAL LIVING- APPENDIX D

Transitional Living- Appendix D

Andrea Fadel


Ithaca College

Transitional Living Survey

Dear

This is to remind you that the transitional living surveys were requested by March 10, 2000. I have not yet received your completed copy of this survey. If you have already returned the survey, thank you for doing so. If you have not, and you still wish to participate in the study, please fill out and return the survey by March 28, 2000. If you have any questions or need another copy of the survey, I can be reached at (607) 275-3059. I appreciate the time and effort you have put in to completing the survey. Thank you.

Sincerely,


Andrea Fadel
Ithaca College Occupational Therapy Dept.
200 Smiddy Hall
Ithaca, NY 14850

Running Head: TRANSITIONAL LIVING- APPENDIX E

Transitional Living- Appendix E

Andrea Fadel

Ithaca College

Dear

I would like to thank you for participating in my research study for my master's thesis. The following pages reflect some of the findings from this study that you requested.

Sincerely


Andrea M. Fadel

Abstract. Mentally retarded individuals face many challenges when transitioning into the community. Among these are difficulties in transitional living skills. Currently there is very little research on community programming for individuals with mental retardation. In this study, a survey questionnaire assessed the transitional practices of occupational therapy personnel in New York State and discovered what elements were most commonly included among transitional living skills. Respondents also rated these elements as important or unimportant.

Overall, occupational therapy personnel were found to work with younger children using a developmental approach, and worked minimally in the transitioning process. Those therapists who work in transitioning, often used the traditional roles of evaluation and individual treatment when working with consumers. The skills that they taught were primarily those that related more to basic ADLs such as feeding or eating, dressing, and oral hygiene, even though they recognized the need for training in more complex IADLs particularly emergency response, medication routine, and health maintenance. Analysis of rural and urban centers did not indicate meaningful differences.

Findings from this study will be useful when identifying effective treatment approaches for mentally retarded individuals who are transitioning into the community. They also reflect a real need for more occupational therapists to provide programming leading to the acquisition of transitional living skills for individuals with mental retardation or developmental disabilities.

Response. The survey questionnaire was mailed to one hundred fifty occupational therapy personnel, randomly selected within New York State from AOTA.

A total of thirty-eight surveys were returned; twenty-six after the initial mailing and twelve, following the second mailing. One of the thirty-eight respondents indicated that she no longer worked in the field of occupational therapy, and returned the questionnaire blank. The remaining thirty-seven responses were used in the data calculations.

Participant Demographics. The work experience level of the participants averaged 8.44 years, indicating a fairly new group of professionals, (see Table 1 below). These individuals indicated that they have worked at their current facility an average of 6.48 years. The mean number of hours worked per week under their job title is 29.83 hours per week, which indicates that most individuals are working full-time.

Table 1

Participant Demographics

	Mean	n	Range	Standard Deviation
Years worked under title	8.44	36	.12-26	± 7.32
Years worked at facility	6.48	37	.12-21	± 6.16
Hours worked at facility	29.84	38	-.00-48	± 11.87

Participant Role. When asked the following question: "What do you feel is your primary role when working with consumers?" the majority of participants (66.6%) stated either evaluation or individual work. Only 13.3% use group work as a primary way of treating consumers, and 13.3% also work on a consultative basis. "Other" was also marked as a way to serve consumers (6.7%). Of the thirty-seven participants, only thirteen (34.2%) work in the transitioning of their consumers, whereas twenty-four (63.2%) stated that they do not work in this area.

Theories Used. The following occupational therapy theories were expressed as being used most often in descending order when working with consumers: developmental theory (twenty-one individuals), cognitive (3 individuals), NDT, Occupational Behavior/MOHO, and other (two individuals), and behavioral, vocational rehabilitation, occupational science, and sensory integration (one individual each). It was found that the

developmental model is used primarily with ages under the age of twenty-one. From that age on, there is a shift in models used, and more emphasis is put on using other models. This trend also held true when cross analyzing the second and third most popular theories used.

Skills Taught in Transitional Programming. Based on the occupational performance list of twenty-eight different skills, the following eleven skills came to the forefront in terms of whether they were taught in transitional programming for mentally retarded individuals:

1. Feeding or Eating
2. Dressing
3. Oral Hygiene
4. Play or Leisure Exploration
5. Self-control
6. Safety
7. Grooming
8. Toilet Hygiene
9. Functional Communication
10. Coping Skills
11. Work Performance

A Likert scale of one to ten, where one meant that the skill was absolutely necessary for transitional programming, and ten meant that the skill was not necessary to transitional programming, was used to discover the perceived importance of these skills when teaching transitioning to consumers. It was assumed those skills given a mean rating of one to four were considered necessary, a score of five was indifferent, and scores falling from six to ten were considered not necessary. A total of five skills: vocational exploration, care of others, sexual expression, yard maintenance, and volunteer participation fell in the range of being considered not necessary (See Figure 1). The majority of the participants deemed all other skills listed as necessary.