Current Trends in Occupational Therapy Services for Adults with Developmental Disabilities in Small Community Living Settings

May, 2011

This research, submitted by Jennifer Anderson, has been approved and accepted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy from the University of Puget Sound.

Renee Watling PhD, OTR/L

Committee Chairperson: Renee Watling, PhD, OTR/L, FAOTA

Lucretia A. Berg, MS, OTR/L

Reader: Lucretia Berg, MS, OTR/L

George Tomlin PhD, OTR/L

Director, Occupational Therapy Program: George Tomlin, PhD, OTR/L

Sarah Moore Ph.D.

Dean of Graduate Studies: Sarah Moore, PhD

Abstract

The purpose of this descriptive study was to assess current trends in occupational therapy services provided to adults with developmental disabilities living in community settings. A survey questionnaire was sent to 52 directors and managers of community living facilities in Whatcom, Snohomish, King, and Pierce counties. The results indicated that the needs of residents are a direct match with the services occupational therapists provide as outlined in the *Occupational Therapy Practice Framework -II* (AOTA, 2008). The results also indicated that people with developmental disabilities still have significant barriers to inclusion in their communities. Occupational therapists and advocates for this population should be made aware of the contributions occupational therapy practitioners can make toward helping people with developmental disabilities achieve a higher level of independence and inclusion.

Keywords: developmental disabilities, community living settings, occupational therapy, deinstitutionalization

In the 1970s, people with developmental disabilities in the United States (U.S.) began to move from state-run institutions into smaller community settings (Lakin & Stancliffe, 2007). Medical and therapy services were provided on-site in institutions to help with things such as activities of daily living (ADL) and instrumental activities of daily living (IADL), behavior management, transitions, and assistive technology (Campbell & Herge, 2000; Hammel, Lai, & Heller, 2002). Occupational therapists play a role in teaching skills for independent living and compensatory strategies to people with developmental disabilities living in community settings. Despite the role of occupational therapists with this population, few studies have critically examined such contributions or offered constructive feedback for improved efficacy of practice in this setting.

Developmental disabilities are defined as "chronic impairments that appear before age 22 and are likely to continue indefinitely" (Parish & Lutwick, 2005) and diagnoses may include mental retardation, autism, and cerebral palsy, among others. According to the National Association of Councils on Developmental Disabilities (NACDD, 2010), approximately 5.4 million people in the United States have developmental disabilities (NACDD, 2010). People with developmental disabilities often spend their entire lives dependant on publicly funded services (NACDD, 2010).

Until the 1960's, people with developmental disabilities primarily lived in state-run institutions (Stancliffe, Emerson, & Lakin, 2001). In the 1970's, the emergence of research demonstrating the benefits of community living, legislation supporting the rights of people with developmental disabilities, Supreme Court decisions such as Wyatt v. Stickney, which established constitutional rights and standards for the care of mentally ill and mentally retarded individuals, and a self-determination movement all contributed to

the depopulation of state institutions (Anderson, Lakin, Mangan, & Prouty, 1998). As a result, the majority of people with developmental disabilities in the U.S. now live in community residential settings, which are defined as settings with no more than 15 residents (Parish & Lutwick, 2005). "While terminology varies by state, these services typically include group homes, foster care, supervised apartments, supported living, and personal assistance" (Parish & Lutwick, 2005). People who live at home with their families are generally categorized under family support and are not included in this definition (Parish & Lutwick, 2005). In 1988, there were 78,173 people living in community settings with six or fewer residents. By 2008, that number had increased to 321,025 (Salmi, Scott, Webster, Larson, & Lakin, 2010).

Occupational therapists help people "engage in everyday activities or occupations that they want and need to do in a manner that supports health and participation" (AOTA, 2008, p. 626). People with developmental disabilities living in the community often need assistance with occupations such as ADL and IADL, assistive technology and home modifications (Hammel et al., 2002), and community participation (Campbell & Herge, 2000). Additionally, the need for services may be escalating due to the increased life expectancy of persons with developmental disabilities. In 2002, Hammel et al. estimated that there were approximately 526,000 individuals in the United States with mental retardation. These researchers projected that this number would double by the year 2060, leading to an increased need for relevant and effective services.

Occupational therapists are uniquely trained to help people engage in life's various activities and occupations. The *Occupational Therapy Practice Framework – II* (AOTA, 2008) defines these areas of activities and occupations as "activities of daily

living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation" (AOTA, 2008, p. 630). One of the main catalysts behind the move from institutions to smaller community settings was the view that people with developmental disabilities have a right to meaningfully participate in desired occupations in an integrated community environment. "The focus of service delivery within the past decade has shifted from teaching the individual new skills to enhancing the individual's quality of life and increasing his/her participation in the local community" (Campbell & Herge, 2000, p. 78). Furthermore, Yerxa, an occupational therapist, described occupational therapy as "the profession able to remove social barriers that prevent individuals with disabilities from achieving their potential and that empower individuals in 'real-life' environments, not institutions" (Cotrell, 2003, p. 21). People with developmental disabilities may be experiencing a higher level of community involvement in terms of residency but full inclusion in terms of participation has not been achieved. Occupational therapists may be able to help this population achieve a higher level of inclusion.

Despite the widespread recognition of the shift of persons with developmental disabilities from institutions to community living settings within occupational therapy literature, there is little current data regarding the need for occupational therapy services among this population, the types of services offered, or whether people with developmental disabilities are able to access occupational therapy services when they are needed.

Background

Life before deinstitutionalization. Prior to the 1960s, people with developmental disabilities lived most commonly in large, state-run institutions, considered to be the standard model of care (Herge, 2003). Institutions supported people with developmental disabilities using the medical model, which deemed this population as sick and in need of caretaking. This service model resulted in the segregation of people with developmental disabilities from society until they were cured. Since there is no cure for developmental disabilities, this meant that many people with developmental disabilities were excluded from their communities for their entire lives. (McCarthy, Reynolds, & Walker, 2003, p. 25). While well intended, this environment provided little choice for residents. Herge (2003) noted, "Daily patterns of activity were nonexistent. Individuals were herded into large day rooms where they spent their entire time waiting for meals, showers and bedtime" (p. CE-2). Furthermore, residents received most of their medical and therapeutic services on-site, and these services "were regarded as limited in quality" (Campbell & Herge, 2000, p. 77).

Civil rights, deinstitutionalization and community living. In the 1960s, the civil rights movement, along with advances in medications, spurred the deinstitutionalization of people with psychiatric diagnoses living in state institutions. People with developmental disabilities began to be included in the civil rights movement and public exposés on the poor conditions and treatment of this vulnerable population received wide spread attention through the media (Anderson et al., 1998). In the 1970s, the "principle of *normalization* gained in popularity" (Herge, 2003, p. CE-2). Normalization was the idea that people with developmental disabilities should have

access to similar routines and patterns as people without disabilities (Herge, 2003). Along with civil rights and the idea of normalization, the Rehabilitation Act of 1973 (P.L. 930112), which recognized the "rights of persons with disabilities to live in and to participate in society," helped drive deinstitutionalization (Anderson et al., 1998, para. 7).

During the 1970s and 1980s, people with developmental disabilities moved in large numbers from state-run institutions into smaller community settings. In 1968, 193,690 people lived in institutions. By 1977, 151,532 people lived in institutions (Anderson et al., 1998). This downward trend continued, and by 1987, this number decreased to 94,696 (Anderson et al., 1998). This trend is also supported by statistics tracking the number of people moving into community settings. "Between 1988 and 2008, the number of people with intellectual and developmental disabilities living in residential settings with six or fewer residents increased from 78,173 to 321,025" (Salmi et al., 2010, p. 168).

Americans with Disabilities Act, Olmstead Decision, and New Freedom Initiative. The shift from institutions to community settings was influenced by the Americans with Disabilities Act (ADA) of 1990 as well as the Supreme Court decision of 1999 known as the Olmstead Decision (see below). Cotrell (2003) reviewed legislation that preceded the Olmstead decision and identified implications for practice, research and advocacy for occupational therapists. She wrote, the ADA "contained provisions to ensure access to public transportation, telecommunications, and public accommodations along with nondiscrimination in employment and government services, activities, and benefits" (p. 17). She stated, however, that ADA legislation has not necessarily benefited all people with disabilities. Most notably, it has neglected to result in the full integration

of people with developmental disabilities. Despite the trend of deinstitutionalization and the clear intention of the ADA, institutions continue to be the only option for many people.

In 1999, the case of two women from Georgia with diagnoses of mental retardation and mental illness that were living in state-run institutions was brought to the Supreme Court. The case, known as Olmstead v. L.C., "asserted that forced continued institutionalization violated the plaintiffs' rights under the ADA to live in the most integrated setting" (Cotrell, 2003, p. 18). The Supreme Court ruled in favor of the plaintiffs, arguing that people with disabilities have the right to live in an integrated community setting, and anything else is a violation of ADA. An issue of concern was how such community settings would be paid for. In response to the Supreme Court decision and the complex issue of funding, the Clinton administration delineated guidelines to assist states with implementing transition of Medicaid funding from institutions to community settings (Cotrell, 2003). Since a large majority of people with developmental disabilities are supported by Medicaid funds, this made transitioning to community settings a more feasible option.

After the Olmstead decision, civil rights cases were filed because the Supreme Court had ruled that people with developmental disabilities have the right to live in the most integrated setting possible. As a result of this Supreme Court ruling, the institutional setting was now a violation of people's rights. In response, George W. Bush's New Freedom Initiative was passed (Cotrell, 2003). The goals of this initiative reiterated the intentions of the ADA. They included expansion of education opportunities, full community access, expansion of transportation opportunities and workplace integration

for people with disabilities (Cotrell, 2003). The New Freedom Initiative was an expansion of the ideology of the ADA and resulted in more insight about the living conditions and service needs of people with developmental disabilities.

The New Freedom Initiative culminated in the formation of the Interagency Council on Community Living (ICCL), which reported significant barriers to community living. These barriers included housing shortages, personnel shortages, caregiver and family support service gaps, inaccessible transportation and employment disadvantages and disincentives (Cotrell, 2003, p. 19). The shift from institutions has led to the disbursement of this population throughout the communities in which they live, and has resulted in some gaps in services in the areas of staffing, transportation, and employment.

The literature reviewed for the purposes of this study supports the areas of need highlighted by Cotrell (2003). For example, issues of transportation, employment, and age-related issues such as transitional services came up frequently in the literature. The issues of autonomy, self-determination, and participation also appeared throughout the literature. The civil rights movement for people with developmental disabilities has moved beyond the issues of basic ADL such as feeding, and is advocating for a higher level of participation because people with developmental disabilities may or may not be able to achieve independence in occupations such as feeding and self-care. The level of participation envisioned by advocates for persons with developmental disabilities is one in which individuals are supported in ways that promote choice, self-advocacy, self-determination, and occupational justice.

Needs of people with developmental disabilities and implications for occupational therapy. The movement of people with developmental disabilities from institutions to community settings led to a shift in the service delivery model for this population. The service model transitioned from one of exclusion and isolation under a medical model, to one of inclusion and integration under a support model. The support model posits that people with developmental disabilities are not in need of a cure, but are in need of support in order to live a life of their choosing (McCarthy et al., 2003).

The model of support and inclusion is one that can be bolstered by occupational therapists. Occupational therapists are trained to examine client factors. For example, neuromuscular functions and body structures that might inhibit an individual with cerebral palsy from successfully navigating his or her environment, or problem behaviors that might inhibit an individual with Autism from participating in community outings might be factors that occupational therapists consider (Herge, 2003). Occupational therapists are also trained in activity analysis. Herge (2003), an occupational therapist, wrote,

> The ability of adults with DD to perform occupations may be affected by their ability to perform simple tasks such as mobility, transfers, feeding, dressing, toileting, and hygiene. In some cases the activity demands exceed what the client is able to perform. (p. CE-3)

In this case, the task or environment might be adapted to increase participation. Occupational therapists are adept at analyzing cognitive and physical skills as well as environments and tasks. The service model under which people with developmental disabilities are supported calls for activity and environmental analyses so that this

population may be as fully integrated as the individual hopes to be, both at home and in the workplace.

An aging population. While deinstitutionalization has resulted in more people with developmental disabilities living in community settings, the increased lifespan of people with developmental disabilities is contributing to higher numbers of people in need of support (Parish & Lutwick, 2005). Hammel et al. (2002) projected that by the year 2030, the number of adults "over the age of 60 with mental retardation and other developmental disabilities" would double, resulting in more than 1 million people with developmental disabilities in the United States (p. 93). Adults with developmental disabilities who live at home during their adult years eventually have aging family caregivers, which may lead to a need for transition services later in life. Herge (2003) described a man who moved from his family home to a group home at the age of 64 after his father died. Not only did this man need help adjusting to his new environment, but having been cared for under the medical model his entire life, he had never learned to feed himself. This man received occupational therapy services and as a result, he was able to learn this skill and achieve a higher level of independence. This case demonstrates that given the opportunity, people with developmental disabilities may be able to learn new skills or utilize compensatory strategies to participate in more desired occupations.

Time for examination of the role of occupational therapy in the Puget Sound region. The potential role of occupational therapy practitioners in helping people with developmental disabilities become fully integrated into society is clear. The move of people from institutions into smaller community settings is also clear. The studies found by the researcher that support the role of occupational therapy interventions for people

with developmental disabilities took place in the 1980s and early 1990s (Carr & Carlson, 1993; Kibele, 1989; Neistadt, 1986; Nochajski & Gordon, 1987) and none were specific to Washington state. Furthermore, Metzel, Boeltzig, Butterworth, Sulewski, and Gilmore (2007), concluded that community residential providers, despite passage of the ADA and the Olmstead Supreme Court decision, are "maintaining a thriving segregated sector" (p. 157). Even though laws have been passed in an effort to bring a higher level of inclusion for people with developmental disabilities, this population may still be experiencing segregation within their own communities.

The residential setting in which people with developmental disabilities live has changed due to deinstitutionalization. Also, this population is growing as a result of increased longevity. Furthermore, the civil rights movement taking place on behalf of and by this population is advocating for a higher level of inclusion along with increased choice and self-advocacy. The extent to which the occupational therapy needs of this population are being met is unknown. The purpose of this study, therefore, was to determine whether there were needs of this population that fell within the scope of practice of occupational therapy and identify those needs that were currently not being met.

Method

Research Design

A descriptive study was conducted to acquire data about the current status of people with developmental disabilities and the types of services they were receiving in community living settings.

Participants

The population of interest for this study included directors and managers of community living facilities in Whatcom, Snohomish, King, and Pierce counties of Washington state. The accessible population was determined by consulting a supported living program directory available on Washington State's Division of Developmental Disabilities website (Washington State Department of Social and Health Services – Division of Developmental Disabilities, 2010). The researcher created a participant list from all names and addresses available for Whatcom, Snohomish, King, and Pierce counties. Geographic location within these counties defined the inclusion criteria. The list was cross-checked for duplications. For those parent agencies that had facilities or offices in multiple counties, only one main office in each county was included on the participant list. The resulting sample size was 52.

Instrumentation

A new questionnaire (see Appendix) was developed for this study that included questions in five sections: demographics, needs of residents, occupational therapy services received, resident activities and autonomy, and employment. The demographic section requested information such as county, city, age of persons served, diagnoses of persons served and average number of residents living in each housing unit (agencies may have had multiple housing units that they managed). The second section used closed-ended multiple choice questions to address the areas in which staff provided assistance to residents and whether professional therapy services were received by residents, and if so, the characteristics of those services. The third section used closed-ended multiple choice questions to address occupational therapy services and the nature

of services provided. The *Occupational Therapy Practice Framework -II* (AOTA, 2008) was consulted in the formation of these questions because it clearly defines the scope of occupational therapy. Questions were developed asking about residents' ability to participate in occupations and any involvement in occupational therapy, and needs related to assistive technology, home modifications, compensatory strategies, support outside the home, communication and transportation. The fourth section used closed ended questions to address issues of residents' activities and autonomy. The fifth section used open ended questions to address issues of employment. A pilot questionnaire was administered to the director of community living at an agency in Seattle, Washington, that provided supported living services for people with developmental disabilities. Feedback was used to make necessary revisions to the questions and format of the questionnaire. As a new instrument, the questionnaire was of unknown reliability and validity.

Procedures

After the study was approved by the University of Puget Sound's Institutional Review Board, survey packets including a cover-letter explaining the study's purpose and information about the researcher, the questionnaire, and a coded business return envelope were compiled and mailed to 52 agencies on the established mailing list. Alpha-numeric codes on return envelopes were used to track returned questionnaires for subsequent mailings. The unmarked questionnaires were separated immediately from the marked envelope which were discarded to maintain confidentiality. Upon receipt of the questionnaires, responses were entered into an electronic database. Three weeks after the initial mailing, replacement packets were mailed to agencies that had not yet responded.

Following data analysis, returned questionnaires were stored in a locked office at the University of Puget Sound.

Data Analysis

Data were analyzed using Microsoft Excel. Descriptive statistics including frequency counts and percentages were used to gain insight about what types of services were provided and how people with developmental disabilities were accessing occupational therapy services. Additional comments provided by respondents were recorded and evaluated for trends.

Results

From the original mailing to 52 programs, 11 completed questionnaires were received. Seven packets were returned due to incorrect addresses. Of the seven marked "return to sender," six addresses were corrected, and one address could not be located. Those six programs with updated addresses only received one mailing. Three weeks after the initial mailing, packets were sent to the 40 agencies that had not responded. Of this group, eight were returned completed and two were returned as undeliverable due to incorrect addresses. Of the 19 programs that returned completed questionnaires, two were omitted because the respondent did not meet the inclusion criteria, leaving 17 eligible surveys. The response rate was calculated by dividing the total number of returned questionnaires (19) by the total number of reachable programs (49), yielding a response rate of 39% (19/49).

Characteristics of the Agencies

Respondents represented four counties in the Puget Sound region (6% Whatcom County, 12% Snohomish County, 65% King County, 17% Pierce County). The 17

responding agencies represented 164 individual community living facilities, with each agency managing an average of 10 separate facilities. The number of clients living in each housing unit ranged from one to eight with a total of approximately 324 individuals represented. The age range of the residents supported was 18 to 79 years. Respondents reported a variety of diagnoses, including mental retardation, cerebral palsy, autism spectrum disorder, and Down syndrome. Eight programs reported "other" diagnoses, including Angelman syndrome, deaf/blindness, spina bifida, and mental health diagnoses such as schizophrenia.

Needs of Residents

Respondents were asked to identify areas in which staff were regularly responsible for providing assistance to residents. All respondents (n=17) indicated that dressing, taking medications, making appointments, arranging transportation, toileting, grooming, and preparing meals were areas in which staff were responsible for providing assistance. Almost all of respondents (94%) indicated that staff members assist residents with communication and selecting and engaging in leisure activities. Eighty-eight percent of respondents indicated that feeding was an area in which staff provides assistance.

Respondents were also asked to identify types of professional therapy services received by residents and whether these therapy services were provided on-site or off-site. Types of professional therapy or consultation services provided on-site for residents include assistive technology, wheelchair fitting/training, mental health counseling, nutrition and exercise, occupational therapy, physical therapy and other. Similar numbers

were reported for professional therapy services received off-site. Complete results are reported in Table 1.

Areas in which respondents reported believing residents would benefit from professional services included accessing leisure activities, accessing employment opportunities, managing or improving problem behaviors, and wheelchair fitting/training among others. Complete results are reported in Table 2.

Occupational Therapy Services

Ten of seventeen (58%) programs reported that their residents receive occupational therapy services in one or more places. Of these ten, 40% reported residents receiving services on-site, 80% reported residents receiving services off-site, 20% reported residents receiving services at work, and 40% reported residents receiving services at adult day programs. However, 41% of the 17 respondents indicated that residents do not receive occupational therapy. Of the residents who do receive occupational therapy services, a variety of areas of occupation were reported as being addressed, with more than 50% of programs reporting occupational therapy services for eating/feeding, wheelchair fitting/training, transportation, and self-care. Complete results are reported in Table 3.

Resident Activities and Autonomy

When asked whether residents choose leisure activities of their choice, 65% of respondents indicated that this is almost always true. The remaining respondents (35%) indicated that this is sometimes true or rarely true. Seventy-six percent of respondents indicated that residents have opportunities to go on outings of their choice. When asked if residents choose their roommates, six (35%) indicated that this is always true, four (19%)

indicated that this is sometimes true, six (35%) indicated that this is rarely true and one (6%) indicated that this is never true. When asked whether residents choose how their disposable income is spent, 11 (65%) respondents indicated that this is almost always true, four (24%) indicated this is sometimes true, and two (12%) respondents did not answer the question.

Three questions were asked regarding resident employment and 16 respondents reported that a total of 106 individuals participated in some kind of employment. Two questions asked about duration of employment and the third asked about the number of residents who were employed. However, responses were provided using variable quantities of data such as days, hours, months and years, which prevented analysis of these data.

Discussion

Needs of Residents

The results indicate that staff who work in community living settings for individuals with developmental disabilities assist people in a variety of areas. While the results do not indicate the exact level of dependence for individuals, respondents indicated that staff members assist residents in activities of daily living such as grooming, feeding and toileting. The *Occupational Therapy Practice Framework – II* (AOTA, 2008) defines the scope of occupational therapy practice and specifies areas of occupation that occupational therapists are specifically trained to address. These include activities of daily living such as eating/feeding, grooming, dressing and functional mobility, as well as instrumental activities of daily living, such as leisure, work, and education. The needs of residents identified by the findings of this study are a direct

match with the occupational therapy scope of practice. Occupational therapists can use their knowledge of activity analysis and environmental modification to help this population become more independent in these areas. Occupational therapists need to be aware of the contributions they can make to help people with developmental disabilities to achieve a higher level of independence and social inclusion, and seek out opportunities to provide such services. Occupational therapy professionals and advocates for people with developmental disabilities need to be catalysts for creating real and lasting change in the lives of people with developmental disabilities.

Interestingly, the respondents' perception of areas that residents would benefit from professional services include areas such as accessing leisure activities, accessing employment opportunities, managing or improving problem behaviors, and wheelchair fitting/training (see Table 2). This data is consistent with the literature, which demonstrates that while people with developmental disabilities have moved from institutions to community settings, they may not have become fully integrated into society because of barriers to things such as employment and leisure (Cotrell, 2003; McCarthy et al., 2003; Metzel et al., 2007).

Occupational Therapy Services

Research published twenty years ago demonstrated that occupational therapy services can help people with developmental disabilities to be more independent in community living settings (Carr & Carlson, 1993; Kibele, 1989; Neistadt, 1986; Nochajski & Gordon, 1987). However, the findings of this study suggest that occupational therapy services are not consistently provided for adults with developmental disabilities living in community settings who may need such services.

Even though a wide range of data was collected regarding employment, only 12% of respondents indicated that residents receive occupational therapy services at work. Occupational therapists are adept at assessing the skills and needs of individuals as well as analyzing environmental demands in order to establish a better fit between person and environment. Therefore, occupational therapists may be able to use their expertise to contribute to an increased level of independence at work, increased options for types of work, or increased hours for people with developmental disabilities. Occupational therapy practitioner involvement in the employment settings of people with developmental disabilities could result in more hours worked which not only increases the self-efficacy of people with developmental disabilities, but is a cost effective way to generate more productivity and less financial dependence for this population. Advocates for people with developmental disabilities and advocates for the occupational therapy profession must encourage legislative action, promote increased funding for employment support services, and work to increase occupational therapy service provision in employment settings.

The data collected indicates that a large percentage of people with developmental disabilities living in the community do not receive occupational therapy services at all (41%). Respondents asserted that this might be an issue of funding. Written statements included: "…OT has decreased in participant lives within the community due to private companies not accepting Medicaid and or Medicare to pay for services." As many clients with developmental disabilities and/or mental health issues must rely on government funding as an only source of income, they are unable to private pay for services. One respondent wrote, "Funding for occupational (as well as other) therapy is the most

determinant factor in whether the people we support use services as opposed to actual need being the deciding factor."

Funding has historically been a problem for this population and will continue to be for the unforeseeable future due to widespread fiscal issues at the local, state, and federal levels. As one respondent pointed out, issues with Medicaid as a payment source may be a barrier between people with developmental disabilities and occupational therapy services. Also, occupational therapy and other professional therapy services are expensive and may not be of top priority to people on a fixed income with limited means. It is important that occupational therapists continue to advocate to local, state and federal decision makers about the cost-effectiveness of the profession and the positive impact that can be made on the lives of those who may benefit from occupational therapy services.

Resident Activities and Autonomy

The data regarding employment and resident autonomy are consistent with the literature and indicate that less than half of residents represented in this study maintain employment and that many residents only sometimes or rarely choose activities, and rarely or never choose their roommates. These numbers indicate a type of segregated inclusion and decreased occupational justice for individuals with developmental disabilities. In her review of the current status of individuals living in community settings and whether legislation such as the Olmstead decision have resulted in a higher level of inclusion, Cotrell (2003) found that there are still significant barriers in areas such as housing, transportation and employment. As Metzel, Boeltzig, Butterworth, Sulewski,

and Gilmore (2007) stated, in spite of deinstitutionalization, we are "maintaining a thriving segregated sector" (p. 157).

As mentioned, people with developmental disabilities have moved in large numbers from institutional settings to smaller, community settings. The level of participation envisioned by advocates for this population is one in which people with developmental disabilities are supported in ways that increase choice, control, self-advocacy and self-determination. The published literature reviewed for the purposes of this study and the results of this study confirm that this vision has yet to be fully realized. While it is clear that people with developmental disabilities who live in small community settings are receiving support in a wide variety of areas so that they might live the most integrated life possible, the data in this study indicate that there is still progress to be made in these areas. Rather than simply providing a room in a community setting, efforts must be made to help people with developmental disabilities provide input about who their roommates are and how their disposable income is spent. Furthermore, people with developmental disabilities should have the opportunity to explore and participate in leisure and employment activities of their choice, so that they might truly experience occupational justice.

Implications for Future Research

This study sought to gain insight into the current needs of persons with developmental disabilities living in small, community settings. While the methodology used was an efficient and economical way to access the greatest number of agencies possible, little depth of information on the exact needs of individuals was acquired. One respondent stated that it was difficult to answer questions because of the wide "variation

of client skills." Therefore, qualitative methodology might result in more insight into the nature of the exact needs of individuals with developmental disabilities, and ways in which occupational therapists might help this population gain a higher level of inclusion. The reported needs of individuals with disabilities are a direct match with the occupational therapy scope of practice. There is a clear need for more research on the specific needs of people with developmental disabilities living in small community settings and the contributions occupational therapists could make toward helping such persons become more independent and integrated. In addition, the available literature exploring these issues is old. The most recent study found by the researcher was published in 1993. Contemporary research is needed considering the shift in residential settings, the change in service delivery from a medical model to a support model, and the publication of the *Occupational Therapy Practice Framework - II* (AOTA, 2008).

Limitations

Since the survey distributed for the current study was a newly developed instrument, the reliability and validity were unknown. The wording of several of the questions may have been confusing to respondents, as indicated by comments written in the margins and questions that were answered partially or incorrectly. This may have impacted data collection and interpretation. More closed ended multiple choice questions might result in richer, more useful data. The results of this study may not generalize to all agencies that provide community living support because of the small geographic location represented and the small sample size.

Implications for Occupational Therapy Practice

The shift in service delivery in recent decades from a medical model in which people with developmental disabilities live in isolation waiting for a cure, to a model in which people with developmental disabilities live and receive support in an integrated community setting, was aimed at allowing these individuals to live a life of their choosing (McCarthy et al., 2003). However, it is clear that aim has not been achieved. While occupational therapists are recognized as professionals able to assist people with developmental disabilities to be more independent in ADL/IADL (Carr & Carlson, 1993; Kibele, 1989; Neistadt, 1986; Nochajski & Gordon, 1987), this is not the only area that occupational therapy practitioners should provide services for these individuals. Yerxa, an occupational therapist, emphasized that occupational therapy is the profession that may be able to help remove barriers to areas of occupation that people with developmental disabilities have historically been excluded from, such as leisure activities, employment, and community mobility (Cotrell, 2003, p. 21). While advocates for people with developmental disabilities acknowledge that ADL will continue to be an area of need, they also advocate for a higher level of participation involving increased choice and self-determination. Service emphasis, therefore, should be on assisting this population to experience true occupational justice.

References

American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process (2nd ed.). *American Journal of Occupational Therapy, 62,* 625–683.

Anderson, L. L., Lakin, C. K., Mangan, T. W., & Prouty, R. W. (1998). State institutions: Thirty years of depopulation and closure. *Mental Retardation, 36*, 431-443.

Campbell, J. E., & Herge, E. A. (2000). Challenges to aging in place: The elder adult with MR/DD. *Physical and Occupational Therapy in Geriatrics, 18*, 75-90.

Carr, E. G., & Carlson, J. I. (1993). Reduction of severe behavior problems in the community using a multicomponent treatment approach. *Journal of Applied Behavior Analysis, 26*, 157-172. doi:10.1901/jaba.1993.26-157

Cotrell, R. P. (2003). The Olmstead decision: Fulfilling the promise of ADA? Implications for occupational therapy. *OT Practice, 8*(5), 17-21.

Hammel, J., Lai, J. S., & Heller, T. (2002). The impact of assistive technology and environmental interventions on function and living situation status with people who are ageing with developmental disabilities. *Disability and Rehabilitation, 24*, 93-105.

Herge, E. (2003). Beyond the basics to participation: Occupational therapy for adults with developmental disabilities. *OT Practice, 8*(21), CE1-CE-8.

Kibele, A. (1989). Occupational therapy's role in improving the quality of life for persons with cerebral palsy. *American Journal of Occupational Therapy, 43*, 371-377.

Lakin, K. C., & Stancliffe, R. J. (2007). Residential supports for persons with intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 151-159. doi:10.1002/mrdd.20148

McCarthy, M., Reynolds, M., & Walker, L. (2003). Supporting persons with developmental disability--a new model. *Bioethics Forum, 19*, 24-30.

Metzel, D.S., Boeltzig, H., Butterworth, J., Sulewski, J. S., & Gilmore, D.S. (2007). Achieving community membership through community rehabilitation provider services: Are we there yet? *Intellectual and Developmental Disabilities, 45*, 149-160.

National Association of Councils on Developmental Disabilities. (2010, November). *About NACDD*. Retrieved from http://www.nacdd.org/about-nacdd/what-are-developmental-disabilities.aspx

Neistadt, M.E. (1986). Occupational therapy treatment goals for adults with developmental disabilities. *American Journal of Occupational Therapy. 40*, 672-678.

Nochajski, S.B., & Gordon, C.Y. (1987). The use of trivial pursuit in teaching community living skills to adults with developmental disabilities. *American Journal of Occupational Therapy. 41*, 10-15.

Parish, S. L., & Lutwick, Z. E. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work, 50*, 345-354.

Salmi, P., Scott, N., Webster, A., Larson, S.A., & Lakin, K.C. (2010). Residential services for people with intellectual or developmental disabilities at the 20th anniversary of the Americans with Disabilities Act, the 10th anniversary of Olmstead, and in the year of community living. *Intellectual and Developmental Disabilities, 48*, 168-171. doi: 10.1352/1934-9556-48.2.168

Stancliffe, R. J., Emerson, E., & Lakin, K. (2001). Community living and people with intellectual disability: Introduction to Part II. *Journal of Intellectual & Developmental Disability, 26*, 5-13. doi:10.1080/13668250020032732

Washington State Department of Social and Health Services – Division of Developmental Disabilities. (2010, August). Services. Retrieved from http://www.dshs.wa.gov/ddd/services.shtml

Table 1

Percent of programs reporting that their residents receive on-site and off-site services

Services Received	On-Site	Off-Site
Mental Health Counseling	40%	67%
Nutrition and Exercise	27%	27%
Occupational therapy	33%	27%
Physical therapy	33%	27%
Wheelchair fitting/training	33%	47%
Other	47%	27%

Table 2

Areas in which respondents reported believing residents would benefit from professional services

Area of need	Percentage (n = 17)
Accessing education opportunities	47%
Accessing employment opportunities	76%
Accessing leisure activities	59%
Accessing transportation	53%
Exploring education opportunities	24%
Exploring employment opportunities	65%
Exploring leisure activities	47%
Home modifications	47%
Managing or improving problem behaviors	88%
Money management	47%
Sexuality	35%
Wheelchair fitting//training	59%

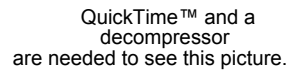
Table 3

Areas in which residents receive services from an occupational therapy practitioner

Area of need	Percentage (n = 10)
Behavioral Issues	30%
Home modifications	30%
Eating/Feeding	60%
Mental Health	30%
Assistive Technology	40%
Wheelchair fitting/training	50%
Staff/resident interactions	20%
Money management	10%
School access	0%
Employment access	30%
Sexuality	0%
Transportation	50%
Self-care	50%

Appendix

Current Trends in Occupational Therapy Services Provided to Adults with Developmental Disabilities Living in Community Settings



In recent years, people with developmental disabilities have moved in large numbers from institutional settings to small community living settings. Medical services were historically provided on-site in institutional settings. The purpose of this survey is to gain insight into the types of occupational therapy services people receive when they live in community settings. This will educate our profession about the areas in which people with developmental disabilities need more assistance and allow for more informed advocacy.

SECTION 1: ABOUT YOUR AGENCY
First, we would like to learn about some of the characteristics of your agency.

1. Indicate which county your agency provides residential services (check all that apply):

☐ Whatcom
☐ Snohomish
☐ King
☐ Pierce
☐ All of the above

2. Write in the number of residential facilities (housing units) your agency manages: _____

3. Write in the number of clients per facility: _____

4. What is the age range of the residents supported by your agency? _____

5. Please write in the number of people to which your agency provides services who have the following conditions as their PRIMARY diagnosis. Include all residents at all facilities.
_____ Mental Retardation
_____ Cerebral Palsy
_____ Autism/Aspergers
_____ Down Syndrome
_____ Cerebral Vascular Accident
_____ Traumatic Brain Injury
_____ Spinal Cord Injury
_____ Other (please list) _____

6. Please indicate the level of training of regular residential staff at each facility and indicate the number of staff assigned to each facility (check all that apply):

☐ Resident care aide # _____
☐ Social Worker # _____
☐ Licensed Practical Nurse # _____
☐ Registered Nurse # _____
☐ Medical assistant # _____
☐ Paraeducator # _____
☐ Other (specify) _____#_____
☐ Other (specify) _____#_____
☐ Other (specify) _____#_____

7. What is the typical resident to staff ratio of your agency? _____

Questions continue on next page

SECTION 2: AREAS OF ASSISTANCE

We would like to know more about the needs of the residents supported by your agency. Please read each question carefully and answer as thoroughly as possible.

8. Of the following, indicate the areas in which your staff are responsible for providing assistance to residents (check all that apply):

☐ Dressing
☐ Feeding
☐ Taking medications
☐ Making appointments
☐ Selecting and engaging in leisure activities
☐ Arranging transportation
☐ Toileting
☐ Grooming
☐ Preparing meals
☐ Communication
☐ Other (specify) _____

9. Of those areas identified in question 8, please list the top 5 areas for which assistance is provided with 1 being the most frequent and 5 being the least frequent.

1. _____
2. _____
3. _____
4. _____
5. _____

10. If your residents receive professional therapy or consultation services ON-site, please indicate the types of professional therapy or consultation services that are provided, the number of residents receiving those services, and whether the service provider is an employee of your agency:

	Services received (circle Y or N for each)		Number of residents receiving these services (write in number)	Services provided by employee of your agency (circle Y or N for each)	
Assistive technology	Y	N		Y	N
Wheelchair fitting/training	Y	N		Y	N
Mental health counseling	Y	N		Y	N
Nutrition and exercise	Y	N		Y	N
Occupational therapy	Y	N		Y	N
Physical therapy	Y	N		Y	N
Other (specify)_____	Y	N		Y	N

Questions continue on next page

11. If your residents receive professional therapy or consultation services OFF-site, which types of expert therapy or consultation services are provided? (check all that apply)

	Services received (circle Y or N for each)		Number of residents receiving these services (write in number)	Services provided by employee of your agency (circle Y or N for each)	
Assistive technology	Y	N		Y	N
Wheelchair fitting/training	Y	N		Y	N
Mental health counseling	Y	N		Y	N
Nutrition and exercise	Y	N		Y	N
Occupational therapy	Y	N		Y	N
Physical therapy	Y	N		Y	N
Other (specify)_____ _____	Y	N		Y	N

12. Based on your professional experience working with this population, in which of these areas do you believe residents benefit from professional services? Please check all that apply:

☐ Exploring leisure activities
☐ Accessing leisure activities
☐ Exploring employment opportunities
☐ Accessing employment opportunities
☐ Exploring education opportunities
☐ Accessing education opportunities
☐ Managing or improving problem behaviors
☐ Accessing transportation
☐ Wheelchair fitting/training
☐ Home modifications
☐ Money management
☐ Sexuality

Questions continue on next page

SECTION 3: OCCUPATIONAL THERAPY SERVICES

The following questions pertain to occupational therapy services received by your residents.

13. In which settings do your residents receive occupational therapy services? (check all that apply)

_____ ON-site (resident's home)
_____ OFF-site (clinic)
_____ Work
_____ Other (specify) _____
_____ None (no occupational therapy services received at this time)

14. Of the following areas, please indicate which of these are your residents receiving services from an occupational therapy practitioner (check all that apply):

☐ Behavioral issues
☐ Home modifications
☐ Eating/Feeding
☐ Mental Health
☐ Assistive technology
☐ Wheelchair fitting/training
☐ Staff/resident interactions
☐ Money management
☐ School access
☐ Employment access
☐ Sexuality
☐ Transportation
☐ Self-care
☐ Grooming
☐ Other (specify) _____
☐ Other (specify) _____
☐ Other (specify) _____

15. Of those areas identified in question 15, please list the top 5 areas addressed by occupational therapy professionals with 1 being the most frequent and 5 being the least frequent.

1. _____
2. _____
3. _____
4. _____
5. _____

Questions continue on next page

SECTION 4: RESIDENT ACTIVITIES & AUTONOMY

We are interested in understanding more about current trends in autonomy for people with developmental disabilities who live in community settings. Occupational therapists often assist people in exploring and accessing leisure activities, social engagement, self-advocacy, and money management.

16. For each of the following statements, please indicate how true the statement is in describing the residents at your agency's housing facilities:

	Almost always true	Sometimes true	Rarely true	Never true
Residents often pursue leisure activities of their choice.				
Residents have opportunities to go on outings of their choice.				
Residents choose their roommates.				
Residents choose how their disposable income is spent.				

SECTION 5: EMPLOYMENT

Occupational therapists may help people with disabilities to be successful at their places of employment. We are interested in finding out if there is a need for occupational therapy services at places of employment.

17. Of the total number of residents in your facilities, how many are employed off-site?

_____

18. What is the range of duration of employment for your current residents at one job?

_____

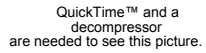
19. What is the average duration of employment for each resident at one job?

_____

Your experience working with this population is greatly appreciated. Please feel free to write down any comments regarding this survey or the population you serve.

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Thank you so much for taking the time to contribute to this study. Please enclose the survey in the provided self-addressed envelope and put it in the mail.



University of Puget Sound
School of Occupational Therapy
1500 N. Warner St. #1070
Tacoma, WA 98146-1070

Acknowledgements

I would like to thank Renee Watling for serving as my committee chairperson, for her guidance and support throughout the research process, for always being available, for listening, and for always having faith in me. I would also like to thank Lucretia Berg for serving as the reader for this study, and for her continuous encouragement. I would also like to thank George Tomlin, for serving as my steadfast leader through the "research jungle."