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Developmental Disabilities and Independent Living: A Systematic Literature Review

Submitted by Benjamin P. Dieffenbach
May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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ABSTRACT

This paper examines the available literature on the correlation between quality of life and type of living arrangement for adults with a developmental or learning disability. The purpose was to examine whether or not adults living semi-independently experienced better outcomes than peers in traditional group homes. In general, outcomes in semi-independent living were equal to or better than the outcomes achieved in traditional group homes, and typically cost the same or less. Impacts on the provision of services and areas for future research are discussed.

INTRODUCTION

The way society addresses the needs of adults with developmental disabilities has drastically changed in the past 30 years. Prior to that time, the vast majority of people with a developmental disability were housed in large-scale institutions (Lakin, Larson, Salmi, and Webster, 2010). Indeed, the population of residents in large-scale state run institutions continued to increase until 1961 (Lakin et al, 2010). Families were encouraged, when their son or daughter with a developmental disability was relatively young, to surrender their legal rights to the child, give the state guardianship over the child, and have them permanently housed in one of these institutions. However, as large, single-issue advocacy groups, like The Arc, a national advocacy organization for people with intellectual and developmental disabilities that has chapters in each state, emerged and began advocating for the rights of adults with disabilities, social expectations about the quality of housing for these individuals began to change.

Services for adults with developmental disability began to move from a “one-size-fits-all” approach to a “least restrictive” approach. Instead of being viewed as a large, homogenous population, adults with developmental disabilities began to be viewed as individuals with desires and goals that needed to be respected in the same way as any other adult. The result of this shift in perception, as well as many scandals that resulted from investigations into the living conditions these adults experienced in state hospitals, was the beginning of large-scale deinstitutionalization (Mansell, 2006).

Although the laws and requirements varied from state to state, most states began to mandate certain amounts of square feet required per client, as well as significantly more stringent standards regarding the quality of care these adults received. In Minnesota, this initially resulted in many clients being moved into what were called Intermediate Care Facilities for the Mentally Retarded (ICF/MR). These facilities were generally large houses or apartment buildings, housing anywhere from 8-20 adults with disabilities. These facilities operated under regulations that were significantly stricter than those that governed state institutions (Lakin et al, 2010).

The reason these residences were called Intermediate Care Facilities, however, was because they were viewed as a stepping stone towards moving clients into smaller, residential settings. As mentioned earlier, in Minnesota, more so than in many other states, deinstitutionalization has taken the form of moving many clients into community based group homes, or SLS. For example, the nationwide average of residents living in residential group home settings was 41.2%, whereas in Minnesota this number was 73.6%. Concurrently, the number of clients renting or owning their own apartment or home was only 4.9% in Minnesota,

as opposed to 15% nationally (Hewitt, Larson, & Lakin, 2000) For this reason, Minnesota provides a uniquely thorough example with which to examine the successes and failures of SLS-type settings. An SLS is generally a home in a residential setting that is owned by either a for- or non-profit company. SLS homes are funded by the state through a Medical Assistance waiver. The waiver program allows the state to waive the rules mandated by the federal government regarding how Medicaid money is spent. Typically, a company will purchase the home, and then use waiver funding from the clients to pay bills, and provide 24 hour staffing for the clients. This was seen as the ideal model for most adults with a developmental disability, regardless of functioning level. Currently, this represents the most common type of residential placement for an adult with a developmental disability in Minnesota. Despite the fact that this model has provided a much better standard of living for adults with developmental disability, it has still largely been a one-size-fits-all approach to the issue (Lakin et al, 2010).

A combination of factors has caused public policy makers and caregivers in Minnesota to reexamine the existing system of primarily placing adults with a developmental disability in SLS style housing. The first factor has been increasing constraints on the availability of funding for these programs. Primarily as a result of the economic downturn, but also as a result of increasing utilization, the SLS model is proving to be a costly option to use for clients who don't necessarily require 24 hour staffing. In addition, there is continued advocacy in the developmental disability community to be more "person-centered", which in this context means evaluating a client's needs and abilities on an individual basis. What caregiver teams are finding is that many developmental disability clients are very capable of living on their own, or

with a roommate, when provided with an adequate level of support services. Not only that, but many of these clients strongly desire to live in more independent settings.

As states like Minnesota begin to explore housing options for client that can provide cost-savings to the state budget and are more developmentally appropriate for clients with a higher functioning level, it is important to examine the outcomes being realized in independent living settings elsewhere. This study will use the format of a systematic literature review to examine the available work that has been done to determine whether or not clients who move from into a more independent living setting are experiencing an improvement in their quality of life as well as an increase in their perceived self-determination. First, however, it is useful to take a more detailed look at how the philosophy and reality of housing for adults with developmental disabilities has changed in the past 50-60 years.

LITERATURE REVIEW

Moving Towards Deinstitutionalization

Although there were many factors that played a role in the move towards deinstitutionalization, one of the most powerful was the development of the concept of *normalization* as it relates to adults with a developmental disability (DD). Normalization, as it was defined in this context, postulated that clients would experience an improvement in their quality of life as they were given greater access to culturally typical activities and settings (Landesman & Butterfield, 1987). As this philosophy was developing, alongside the idea of *least restrictive environment*, it was initially considered fairly radical. Prior to this time, adults with a

developmental disability were considered objects of pity, not adults with valid goals and desires.

Normalization became not just a philosophy but a concrete framework that could be used to evaluate the quality and effectiveness of services for adults with DD. As described by Wolfensberger (1972), normalization is the “utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.” This framework created the impetus for the deinstitutionalization of adults with DD, but also challenged society to provide for these adults in a more effective, humanizing way. Another definition of normalization that developed was the idea that adults with a developmental disability “should have their desires and choices respected, and should be able to live as non-disabled people do”. (Parish, 2005, p. 219) As the DD field moved in this direction, more and more research was done to examine whether or not adults with DD were experiencing improvements in their quality of life as they moved into less-restrictive settings.

A difficulty experienced by professionals working towards deinstitutionalization has been developing effective means of measuring client improvement. Many measures, like “happiness” or “quality of life”, can have different meanings across generational and cultural lines, and can also be difficult to quantify. Measuring changes in the utilization of community leisure resources has been one method used to attempt to quantify improvements in quality of life for deinstitutionalized adults. Baker (2007) used the Guernsey Community Participation and Leisure Assessment (GCPLA) to examine changes in adults that were discharged from a community hospital in the UK. These recently resettled adults were compared to a control

group of residents who already lived in community residential services. He found that residents who moved out of institutions saw a statistically significant increase in their utilization of community resources when compared to the control. Despite this fact, however, these clients still rated much lower than adults with DD who had not resided in an institution, and other typical adults, suggesting lingering effects as a result of institutionalization (Baker, 2007).

Another method of measuring progress has been to examine behavioral outcomes of clients that move from an institution to a more residential setting. One unknown in the move towards deinstitutionalization was the extent to which clients would be able to develop adaptive behaviors and what changes would occur in regards to challenging behaviors that clients had previously exhibited. In this instance, adaptive behaviors were defined as changes in basic skills of independent daily life associated with movement from institutional to community residences (Policy Research Brief, 2011). An examination of a number of studies over the span of 30 years found consistent evidence of clients experiencing positive changes in adaptive behavior (Policy Research Brief, 2011). There was less consistency in the changes that occurred regarding challenging client behavior. Many of these studies confirmed what advocates of normalization believed: that given the opportunity, many of these clients were capable of providing for many more of their needs than they were being given credit for.

Similarly, O'Brien, Thesing, and Tuck (2001) examined in a qualitative study the perceptions of family members and caregivers to the changes they saw in adults with DD as they moved into community-based residential housing after a long stay in an institutional facility. They found, similar to other studies, that despite long histories of institutionalization, clients showed an impressive ability to demonstrate increases in their social and adaptive skills.

Other positive benefits that family and caregivers identified in the move to residential housing were that the person led a “normal” life, had more variety in their activities, and a larger group of people in their life that cared for them (O’Brien et al, 2001) Despite the success that has been witnessed in the deinstitutionalization movement, it is also important to more closely examine the community-residential housing movement to look at its successes and failures, as well as how it has spawned the Independent Living movement.

Community-Residential Housing: Opening New Doors

Nationally, the results of deinstitutionalization as a policy are stark. In 20 years, between 1988 and 2008, the number of adults with DD living in a residence with 6 or fewer people increased 311%. Additionally, every state but one saw more than a 100% increase in adults with DD living in a residence of 6 people or less (Salmi, Scott, Webster, Larson, & Lakin, 2010). Beginning in 1978, the number of admissions to large public facilities has been lower than the number of discharges every year (Lakin, Larson, Salmi, & Webster, 2010). This was an important metric for measuring the pace at which deinstitutionalization was occurring.

When making comparisons between an SLS-type setting and living situations in which the client is living more independently, it is important to remember that all of these comparisons should be viewed as relative to the living conditions and quality of life adults with DD experienced in institutions. Despite the fact that SLS houses do not always compare favorably to more independent options, they still provide a much higher quality of life, significantly more independence, and better outcomes for adults with DD than institutions ever did. For instance, Hewitt et al (2000) reported in regards to SLS type services, that in general

“Consumers generally liked the places they lived and worked. Most families were satisfied with transportation, residential services, and case management services. Families reported most of the time and in most settings staff members were understanding, respectful, professional, and caring. Case managers and waiver coordinators reported that when compared to ICF/MR services, HCBS (Home and Community Based Services, of which SLS are a part) services were superior with regard to people having choices, privacy, feeling at “home”, participating in their community, picking where and with whom they live, small size of home, and staffing ratios.” (p. 18)

These results would likely be even starker when compared to large-scale institutions as well.

Research done on the effects of deinstitutionalization of adults with DD into smaller, residential settings, has continually shown that SLS-type housing provided outcomes for adults with DD that were significantly better than those received from large-scale institutional care. For example, Kozma, Mansell, and Beadle-Brown (2009) found that community based services generally offered more choice and opportunities for client self-determination than large facilities. Most importantly, they found that when using an objective quality of life measure that generally the clients fared much better in the community. In general, most research consistently showed that client’s saw improvement in all areas of adaptive skills, including self-care, communication, social skills, community living skills, and academic skills (Stancliffe & Keane, 2000; Lifshitz, Merrick, & Morad, 2008; Emerson, Robertson, Gregory, Kessissoglou, &

Hatton, 2000). In addition, one important benefit of living in SLS-style housing, especially when compared to more independent options, is the availability of medically trained staff.

Cardiovascular problems and diabetes were found at a lower rate among clients who lived in residential care. This is likely as a result of the around the clock medical care clients have access to, as well as more stringent nutritional controls (Lifshitz et al, 2008).

Community-Residential Housing: The Downside

Despite the fact that there has been consistent improvement in measures of quality of life for adults with DD moving into the community, one issue has been trying to understand what causes disparities in the level of success that client's experience. As Mansell (2006) points out, although community-based service models consistently achieve better outcomes than large institutions, within the field of community-based services wide disparities in success remained. More strikingly, research consistently shows that there is little correlation between the amount of money spent in a particular program and the level of quality outcomes the clients are receiving (Emerson et al, 2000; Mansell, 2006)

Mansell's research indicates that despite the many benefits accruing to adults with DD as a result of deinstitutionalization into SLS-type housing, not enough is being done to ensure consistent standards of quality between programs. Additionally, not enough effort is focused on research and training in best practices related to helping clients succeed in residential settings (2006). Similarly, as Parish (2005) identifies, significant disparities remain among states in terms of the scale of support services available. Facility-based service is still common, and many SLS programs do not individualize their supports enough to be considered best practice.

It is important to more effectively understand what “works” when moving clients from institutions to an SLS-like setting in order to ensure that clients who are capable of living even more independently will receive the correct supports that will ensure their success. Specifically, Mansell (2006) addresses what he terms “de-differentiation”. This is the idea that SLS providers still attempt to use generalized policies and structures for people with a wide variety of abilities and needs. It is essentially the “institutionalization” of residential homes, despite the fact that the clients are living with relatively more freedom. He describes the importance of addressing this issue as it pertains to SLS homes, but it is also pertinent in designing support services that are flexible and relevant to DD adults living independently.

This idea of the “institutionalization” of residential care facilities is especially important when considered in the context of self-determination. Although SLS provide a higher quality of care than clients were provided in an institution, this setting in many ways still struggles, because of its organizational nature, to allow clients significant self-determination. In part, this is because in each home, there are a number of clients with varying needs. Like any home, it is often difficult to tailor rules and procedures so that each client is treated differently, not only because of logistics, but also because of interpersonal considerations between clients. Additionally, because many of these homes are operated by larger companies, for the sake of efficiency rules and policies are likely developed at the corporate level, as opposed to house by house. This is especially pronounced when dealing with companies that are for-profit, because they must balance and manage the tension between providing the most independence and highest quality of care for the client with the profit motive (Keigher, 2000).

Hewitt et al (2000), when examining the quality of services among Minnesotans utilizing HCBS services, specifically SLS, noted a number of concerning findings. For example, in a survey of adults utilizing these services, they found that 25% stated direct support staff had entered their room without knocking; 19% stated that there were restrictions placed on their phone usage where they lived; and 33% stated that their mail had been opened without permission. Many of these same adults, 72%, reported that they felt they had no input on such major life decisions as choosing whom they lived with. These types of intrusion into an adult's private life would be considered unacceptable in any other setting.

Despite these findings, SLS-type housing remains an appropriate form of care for DD clients that have a moderate to low functioning level, or have complex health and behavioral needs. For example, adults with a diagnosis on the Autism Spectrum present unique and significant challenges when determining an appropriate residential setting. Many of these adults display significant impairment in adaptive functioning. This impairment becomes more significant as the severity of Autism Spectrum symptoms increase. Additionally, these adults showed deficits in areas that are specific to independent living, like dressing, grooming, and hygiene (Matson, Dempsey, & Fodstad, 2009). More importantly, 24-hour staff with medical training makes it possible for these clients to receive semi-complex medical care in an environment that is less restrictive than an institution or nursing home.

For DD adults that have a higher functioning level, however, the relative lack of choice and independence that continues to exist in SLS-type residential settings presents a challenge to the community of caregivers that work with these clients to find a better alternative. There are a number of reasons for this. The first is that for clients who have the ability to live in an

independent setting, there are many options that are either cost neutral, or actually cost significantly less than SLS-type residential settings. Secondly, in many instances independent living settings are able to provide a quality of life for a client that is the same as an SLS or better. Research has consistently shown that clients who are capable of living independently experience improvements in a variety of measures.

For example, research done on a program in Oregon that was moving capable clients out of SLS-type housing into supported living found that the cost of providing services in the independent setting was neutral when compared with an SLS (Howe, Horner, & Newton, 1998). For the purposes of their study, supported living was defined as “people with disabilities living where and with whom they want, for as long as they want, with whatever support is necessary to make that choice possible.” Additionally, clients that were moved into supported living participated in a greater variety of community activities, and participated more frequently, than those living in SLS-type housing (Howe et al, 1998). This article is examined in more detail later. Similar research found that although outcomes in many comparisons of the two living settings were similar, the instances where they were different consistently favored supported living (Stancliffe et al, 2000). Additionally, this research showed that there were no outcomes in which group home participants obtained significantly better scores. For clients living in a group home, per-person staff-support hours and other per person expenditures were consistently and substantially higher than the costs of people living independently with supports.

As previously mentioned, economic realities have caused policy makers everywhere, but specifically in Minnesota, to reexamine the policy of using SLS-type housing as a one-size-fits-all solution to the issue of providing housing and services for adults with disabilities. Not only can

it be fairly expensive, but the level of staffing and care provided is unnecessary, and many times unwanted, for clients with a higher level of functioning. Clearly, SLS-type housing represented a drastic improvement over institutional living, and research clearly demonstrated that client outcomes were measurably better. However, the cost of this service, and the potential for cost savings, has brought new momentum to the move towards normalization and independent living. For example, in 1998 the average cost in Minnesota for a client that lived with a foster family was \$31,518 year. In a corporate foster care (SLS) setting, the average yearly cost per person was \$54,733. This is in stark contrast to the cost of a person who lives in their own home, \$21,454 a year, or with their family, \$19,568 annually (Hewitt, Larson, and Lakin, 2000). The cost and behavior benefits have already been examined here, but it is important to look at the benefits and positive outcomes achieved as a result of allowing clients to have more self-determination in their lives.

Self-Determination and Independent Living

Although the topic was briefly discussed earlier, self-determination for clients with a developmental disability is so important that it bears more thorough examination. Ultimately, the purpose of deinstitutionalization was to focus on providing DD clients with the highest quality of life possible. This was the impetus for continually increasing staffing ratios as clients were moved out of institutions, and for the development of the plethora of services that exist to provide typical life experiences for adults with DD. However, as time has gone on and more research has been done into what contributes to increasing the quality of life for adults with DD, findings have consistently shown that providing opportunities for clients to play an active

role in the daily decisions that affect their lives has a tremendously positive impact on their quality of life. As states like Minnesota look for cost savings at the same time as they seek to find improvements in DD services, it is important to understand the ways in which involving DD clients in the process will result in more positive outcomes for this population.

When thinking about the importance of self-determination for adults with DD, it is important to distinguish between self-determination and success. One of the trademarks of DD services, from institutions to community residences, has been an overriding paternalism on the part of caregivers. There is a sense that caregivers are there to “take care of” clients and to prevent anything bad from happening. For example, Brown (1989) found that in many instances, the placement of a client within a group home setting was often the result of anxiety by professionals and relatives who felt they were responsible for “protecting” the person. However, as any person will attest, being able to make important choices for yourself is not always the same as making the *right* important choices for yourself. Instead, as Wehmeyer (1997) points out, self-determined behaviors are not always successful and will not always have a positive outcome. The important point is that the client is able to act as the primary causal agent in their life, for better or worse (Wehmeyer, 1997). As Brown (1989) states,

“Expression of choices and concerns should be encouraged and individuals enabled to deal with them. Very often care results in physical protection but psychological and social damage. Disability and aging should not be associated with external denial of initiative and risk taking.” (p. 557)

Despite the possibility that the outcomes of promoting more self-determination and independence for clients will not always result in positive actions on behalf of the client, this philosophy still represents a great opportunity for increasing the quality of life for many adults with DD. Indeed, it represents value for the rights of individuals to make choices for themselves (Wehmeyer & Bolding, 2001). Additionally, any possible negatives are greatly outweighed by the consistent research that shows clients who have more self-determination experience a higher quality of life than clients without that level of independence. Treece, Gregory, Ayers, & Mendis found that the independence to choose what is preferred by the client was a key to achieving satisfaction with one's life (1999). Similarly, a study with an international sample found that the characteristics of self-determination predicted membership in a high quality of life group (Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, & Verdugo, 2005). Concurrently, people who lacked self-determination experienced a less positive quality of life (Wehmeyer, 1997).

It has been clearly demonstrated that self-determination is an important factor in achieving a high quality of life. However, self-determination and independence are not interchangeable. An individual exercising self-determination may choose to live in an SLS-type residential setting. Independence, on the other hand, can be understood as the client doing as many things for themselves as possible. In an SLS-type setting, however, many tasks are performed for a client, regardless of need. Significantly, opportunities for people with DD to make their own choices were often overlooked by staff and professionals in SLS housing (Treece et al, 1999) Independence for a client would dictate that the client determines the living arrangement and level of support. The important factor is that the choice was theirs, not

someone else's. It is also important to remember that many of these individuals are capable of improving their capacity for self-determination over time, when given appropriate support and training. Sheppard and Unsworth (2010) found that clients who participated in a program designed to increase their self-determination had all begun demonstrating more self-determination, in a variety of settings, at the end of the program.

Previously, however, little thought was given to whether or not a client was *choosing* to live in an SLS-type setting. It was simply assumed that this type of housing was the best option for *all* clients. What is being discovered is that for many clients, assuming that this type of housing was best for them removed from them the choice of where and how to live. Caregivers and families are learning that many clients, if given the choice, would prefer to live independently, with supports if needed. More importantly, research consistently indicates that when clients are given the opportunity to live at the highest level of independence possible, that they demonstrate a higher quality of life than clients who are not given that opportunity.

It is clear from the literature examining the transition from institutions to relatively small group homes that as adults with DD are given more independence and self-determination relative to their abilities quality of life and self-determination are increased. The next evolution of housing for adults with DD will likely be some form of independent housing, for example an apartment, with minimal staffing supports. For this reason, it is important to examine more specifically whether or not the trend of increased independence equaling increased quality of life carries over to settings that place a high level of responsibility on the client for self-sufficiency.

METHODS

Selection Methodology

There were a number of factors that were considered when the selection process began. Most importantly, only articles that were found in academic journals, preferably peer-reviewed, were accepted. Another requirement was that the articles examined people who had been diagnosed with some sort of developmental or intellectual disability. Finally, this study was looking for articles that examined the impact that housing had on a variety of quality of life measurements. These criteria presented some difficulty. Initially, the goal was to specifically examine whether or not clients with a developmental disability experienced an improvement in their quality of life when they moved out of a more traditional group home setting into some sort of semi-independent living situation. There does not currently seem to be a great deal of research examining this specific topic; this will be discussed more later.

Instead, the focus of the study expanded to look more generally at the impact that different types of housing had on quality of life measures, with an eye towards looking at the outcomes that are achieved for clients living in a semi-independent setting. For the purposes of this study, traditional housing services were defined as having more than 3 clients living together, either in a home or an apartment, with either direct staff support 24 hours per day, or a 24 hour staffing plan. Additionally, all clients needed to have some sort of developmental disability diagnosis. Semi-independent or independent living services were defined as housing with no more than 3 residents living together, with or without a developmental disabilities diagnosis, and less than 24 hour staff support. For example, some semi-independent living programs will provide a small amount of hours of direct staffing per week, generally to assist

clients with budgeting, meal planning, and other needs, but will also provide an emergency phone number that clients can contact 24 hours a day. This would still be considered a semi-independent living program. The articles examined here all examined housing schemes that generally fell within these definitions. Depending on where the studies were conducted, the definition of what constituted supported or semi-independent living varied slightly, but was generally consistent.

SYSTEMATIC LITERATURE REVIEW

Housing Schemes and Quality of Life

Howe, Horner, & Newton, 1998

Although it was cited earlier, the quality of the study done by Howe et al (1998) regarding how different housing, specifically a direct comparison between supported living and traditional residential services and how they affect quality of life, bears a more thorough examination. One important component of this study was the use of matched comparisons. This is a concept that appears regularly in the literature comparing the outcomes of different housing schemes. Although it creates some issues in terms of the constraints placed on the population and the fact that participants were not randomly assigned, it is an important control that is used to make sure that as much as possible, difference in outcomes can be attributed to housing scheme, and not differences among clients.

Initially in this study, of a population of 167 clients who met the state definition of living in supported living, 20 were randomly selected to participate. Once these 20 clients were chosen, 20 individuals receiving traditional supports were randomly selected from a list of all

individuals receiving traditional supports in the state. They were, however, matched to the clients who had previously been selected by being within 4 years of age and of a similar level of developmental disability as the other group. The study developed an extensive operational definition of the features of supported living. Among the most important factors were that the client had significant control over his or her roommates, level of service, initial planning, location, daily life, and daily decision-making. Additionally, the client had to either be the owner of the residence or have their name on the lease agreement if it was a rental. All 40 individuals were then interviewed. They were all asked questions to determine their level of supported-living, community activity, and social engagement. If clients were certified as living in a supported living scheme, but their answers did not match up with the operational definition of supported living, their responses weren't used. Similarly, one client who was certified as receiving traditional services met the operational definition of supported living.

The study found a number of statistically significant outcomes that are worth examining. First, clients living in supported living were more likely to have roommates who did not have a disability. In addition, these clients were more likely to participate at a greater frequency in a larger variety of community activities than their peers in traditional services. Finally, individuals living in supported living were more likely to participate in activities with a larger variety of people than their peers in traditional housing. Overall, Howe et al (1998) found that there were a number of outcomes where individuals in supported living showed a statistically significant advantage to their peers in traditional housing. More importantly, there was not found to be a statistically significant difference in cost, indicating that for clients who have the desire and ability, supportive living can provide improved outcomes for the same cost.

Stancliffe & Keane, 2000

Stancliffe & Keane (2000) followed a similar model to the previous study. They used the population of people with developmental disabilities in the UK who were currently living in some type of government operated housing. For the purposes of their study, they defined semi-independent living as “a household of 1 to 4 people living together with regular part-time support by paid staff...there is no regularly scheduled overnight staff support. On average, the household is without paid staff support, for at least 28 waking hours per week when residents are home.” (Stancliffe & Keane, 2000, p. 283) Group homes, on the other hand, always had awake staff when residents were present and awake. Similar to the previous study, after data was collected all residents in the group homes were matched with a semi-independent client of a similar functioning level. The goal, as the authors described, was to make sure that the clients being compared had “equivalent support needs”. (Stancliffe & Keane, 2000, p. 285)

In addition the residents that were interviewed, staff that worked with the clients were also asked to fill out questionnaires regarding the clients they worked with. Participants in the study were interviewed regarding 4 main categories: aloneness, social dissatisfaction, safety, and quality of life. For the purposes of space, all of the individual inventories and interview tools that were used will not be listed here. Later in the discussion, the reliability of different interview tools and how that affects the results of studies like this will be examined. As previously mentioned, after all of the data was gathered, residents were matched and then compared using paired t-tests.

Of the 27 outcomes that clients and staff were asked about, there were 5 outcomes where there were statistically significant differences between the two groups being examined,

all favoring the clients in semi-independent living schemes. 2 of the outcomes where there were differences were the result of client interviews. The other 3 were the result of interviews with staff. The 2 areas where clients reported better outcomes regarded social dissatisfaction and empowerment. The questions where they fared better when the results were from staff regarded frequency of use of community places, number of community places used without staff support, and participation in domestic tasks. Contrary to the previous study, Stancliffe and Keane (2000) found that the costs for semi-independent residents were significantly lower than their peers living in group homes. Most importantly, although many of the outcomes did not show much difference between the two living arrangements, it is worth noting that there were no outcomes where the group home out-performed semi-independent living, whereas residents in semi-independent living showed better outcomes in 5 categories.

Felce, Perry, Romeo, Robertson, Meek, Emerson, & Knapp, 2008

Similar to the previous two studies, Felce et al (2008) used a matched pairs comparison to examine the outcomes achieved in fully staffed group homes and semi independent living situations. Indeed, this study was intended as a follow-up to the Stancliffe and Keane (2000) study, in an attempt to address what were perceived as some of the methodological limitations. There were 35 clients in each group, and clients were drawn from agencies in the UK that provided services to people with developmental disabilities. The criteria to define a group home and a semi independent living situation are very similar to those used in the previous study done by Stancliffe and Keane (2000). A group home was defined as having a staff presence during all waking hours in which there were clients present. A semi independent living

situation was defined as having a minimum of 28 hours per week where there was no staff support. Additionally, there was no consistent night time support. Researchers interviewed each of the clients, as well as senior staff in the facilities. Participants were asked a variety of demographic questions, as well as questions intended to measure a variety of quality of life issues. Finally, researchers examined the costs of the different services that clients utilized in each setting.

The results of this study presented a mixed bag with regards to quality of life issues. There were a number of areas where clients in semi-independent settings demonstrated lower outcomes. The greatest deficits seemed to be with regards to personal healthcare. The semi-independent residents were found to be less likely to have had their sight tested and to have had worse healthcare related to lifestyle threats. Additionally, they were found to be less likely to live in a house with a garden, have greater problems with money management, and participated in a smaller variety of community activities when compared to their peers in a group home. On the flip side, however, they were found to be more independent in the community, more likely to have people outside of their family, staff, and others with a developmental disability in their friend group, and to participate more in household domestic tasks. Finally, the average weekly cost for a client in a semi independent living situation was found to be less than 1/3 the cost of a client living in a group home (\$542.10 vs. \$1,539.00; Felce et al, 2008, p. 96) All other areas that were examined did not demonstrate a statistically significant difference between the two groups. It will be important to discuss later how to appropriately establish priorities in terms of quality of life issues and cost savings.

Schwartz, 2003

Unlike some of the previous studies discussed which were specifically examining how housing affected quality of life measures, Schwartz (2003) chose to look at a larger variety of life characteristics that could have an impact on a client's quality of life. Housing was included in this list. The study of this design allowed for more randomization in terms of the sample. The facilities that participated in the study were randomly selected from an Israeli government provided list. The only requirement was the clients were verbally articulate and able to answer questions. The sample was comprised of 247 adults with an intellectual disability. The primary tool used to examine clients quality of life was the Lifestyle Satisfaction Scale (Schwartz, 2003), which asked a variety of questions regarding happiness with current residence, happiness with friends and free time, happiness with community services, and happiness with work. Clients that participated in the study lived in one of three types of residences. Group homes were detached houses with 9-18 residences and 24-hour staffing support. Semi-independent apartments had 3-8 residents in an apartment building with scheduled staff support when residents were home, as well as night staff. Finally, independent apartments housed 2-6 residents, had no scheduled staff support, although staff typically provided a couple hours a week of support, and had no night staffing (Schwartz, 2003).

The results of this study are interesting in how different they are relative to the previous studies examined. Schwartz (2003) found that with the exception of the question asking about happiness with current residence, there was no statistically significant difference on any of the other measures between residence types. Clients living in an independent apartment expressed the most satisfaction with their current residence. Group home residents scored higher on all

other measures. Residents living in a semi-independent apartment scored lower than both group homes and independent apartments on all measures. In general, the study found that client's personal characteristics, including adaptive and challenging behaviors, were more predictive of lifestyle satisfaction than living arrangement.

McConkey, 2007

As opposed to broad-based surveys intended to examine quality of life, McConkey (2007) sought to more specifically address and examine the issue of social inclusion. In addition, instead of engaging the clients, McConkey used a survey that was directed solely at the key staff person for each resident. The goal of this study was to determine if there were statistically significant differences with regards to social inclusion between residents who lived in a type of supported-living scheme and residents who lived in more traditional housing settings. McConkey's sample was drawn from residents in Ireland who have a developmental disability and are receiving housing services.

The residents about which data was gathered lived in one of five types of living schemes. The first was dispersed supported living, in which the client generally held the lease and support staff was organized on a regular, but not frequent basis. Generally these clients had roommates. Clustered supported living consisted of apartments or houses that were near each other with shared staff. A small group home was approximately 6 people living in a house that is owned by a service provider and has a 24-hour plan of care for the residents. A residential home averaged 19 residents with 24-hour awake staff. Finally, a campus setting

consisted of groups of houses on the same site with generally 6-8 residents per house, but as many as 100 living in close proximity. This also included 24-hour awake staff.

McConkey's (2007) findings generally lined up with the body of literature that currently exists. The study found that the two biggest predictors of social inclusion were type of accommodation and social competency. It was found that in general, clients living in a supported-living scheme were more likely to regularly access community resources when compared to those living in a traditional group-home style arrangement. However, within those results, when the social competency of each client was examined, those with more developed social abilities were found to be more likely to be active in the community.

Emerson & McVilly, 2004

Instead of focusing on the more general topic of quality of life, Emerson & McVilly (2004) more specifically examine the different factors that can facilitate relationships in the lives of people with an intellectual disability. Living arrangement, in this case, happened to be just one of the variables that were examined when looking at what facilitates successful and long-lasting friendships in this community. This study did not get into specific definitions of each type of housing. However, the sample was broken down by the number of residents in each dwelling, and was taken from the population of people with an intellectual disability in the UK. A useful way of interpreting the data is provided by Table I (Emerson & McVilly, 2004, p.193). The sample is broken down by a variety of factors. The ones of most interest to this review are the breakdown of setting size in terms of the number of co-residents, and examining the type of home. For example, of the 1,542 residents on which information was gathered, 560

lived in a residence of 3 people or less. Additionally, 840 of the residents either owned their home or held tenancy on the lease. It can be inferred from this information that a sizeable chunk of this population were living in what could reasonably be considered to be a semi-independent living arrangement.

Similar to McConkey (2007), Emerson and McVilley (2004) focused on interviewing key staff as opposed to directly interviewing clients. A number of measures were used to collect demographic information, information regarding the social and relational activities of the clients, and information regarding the level of adaptive and behavioral ability of each client. There were a number of findings from this study, but the result that is most pertinent to this review was that living arrangement was a more significant indicator of how often a client would participate in friendship activities than any personal characteristic. More specifically, Emerson and McVilley found that clients who did not live in a registered nursing home were 58% more likely to have participated in a public activity with a friend. An interesting note was that one particular locality of all the areas that were surveyed in this study had clients who showed a much higher likelihood of having participated in activities with friends. This geographic disparity is worth addressing further in the discussion.

Emerson et al, 2001

The final article that explicitly looked at the effect that living arrangement had on quality of life measures also took place in the UK, and involved the interviewing of a sample of residents and key staff. Emerson et al (2001) attempted to get a sample size of 300 by recruiting from human service providers in the UK. They ended up with 281 residents with a

variety of service providers. Unlike previous studies that specifically recruited equal numbers from each type of living arrangement they were examining, this study simply focused on a sample size. Once clients had consented to participate, demographic information was gathered and an operational definition of what qualified as a supported living arrangement was developed. For this study, supported living arrangement was defined as a residence that was described by the provider as such, was not registered as a residential care home or nursing home, and had no more than 3 residents with a developmental disability (Emerson et al, 2001).

To gather information, a questionnaire was developed and both residents and key staff were asked questions about a variety of topics including how staff did client planning, community involvement, abilities and skills of residents, presence of challenging behavior, and health and lifestyle choices. Finally, service providers were contacted regarding cost information. No attempt was made by researchers to pair residents based on age or ability. The findings of this study were generally consistent with other studies done on this topic. Clients living in a supported living arrangement were found to have greater choice and self-determination in a variety of areas, including roommates, living location, and community activities. Interestingly, there was found to be no statistically significant difference in the expressed satisfaction of clients based on living arrangement. It is worth noting that despite the positive outcomes related to choice, clients living more independently were also more likely to have experienced vandalism and more at risk for exploitation, as well as having social networks that were smaller than those of their peers in group homes (Emerson et al, 2001). In this instance, costs for supported living were found to be similar, if not slightly higher, than the cost of a small group home.

DISCUSSION

The research that has been done regarding the topic of how housing schemes can affect quality of life raises a number of interesting points worth discussion. First, it is worth noting that there is not a great deal of research currently available on this topic. More specifically, little research has been done examining how quality of life measures change for people moving from a more traditional housing setting into a semi-independent living scheme. As noted earlier, much of the research that has been done makes use of matched comparisons. The purpose of this is to eliminate as much as possible other variables, for the purpose of study, that would impact a client's experience of their living situation. This tactic raises two issues. The first is that use of matched samples raises issues of validity. For this reason, the fact that the samples being used are not random must be taken into account when considering how the data can be generalized to the larger DD population. Secondly, the use of matched samples indicates that there is a certain cut-off point in terms of client functioning and ability where semi-independent living would not be feasible. Future research would benefit from a more uniform description of what skills and abilities are considered necessary for a client to successfully live semi-independently in the community.

A second consideration raised by this body of research is the fact that there is no uniform definition for what constitutes semi-independent living. Although most of the studies are relatively consistent on how they operationalize this term, there continues to be enough variability that generalizing results can be difficult. It would be helpful for a future study to focus on more specifically defining what can be considered semi-independent living. Issues that should be defined more specifically include staffing patterns, number of residents in a unit, and

who holds the lease on an apartment or home. A more specific definition of semi-independent living would help make studies that examine the outcomes of housing schemes more useful in generalizing.

Another interesting point that arose from these studies was the disparity of service that arises geographically. Emerson and McVilley (2004), among others, found in their study that there was one particular locality of they examined that had statistically better outcomes for people living semi-independently than the other areas that were considered. The potential for disparities in service is a concern not only for policymakers, but for the researchers attempting to inform them by studying the outcomes of these housing schemes. This goes back to the fragmentation in terms of what is defined as semi-independent living. How that term is defined will have a significant impact on how a particular program is implemented. In addition, it emphasizes the importance of not just providing the opportunity for independence, but also making sure that providers and staff are adequately trained to support clients in these settings.

Finally, as mentioned previously, the current economic climate has put pressure on policymakers to find cost-savings. One area that has been targeted is funding that goes towards paying the costs of programming and living for people with developmental disabilities. Although the studies examined here have been fairly consistent in showing that semi-independent living is either cost neutral or provides cost savings, it is important to make sure that the potential for savings is considered within the context of continuing to ensure a level of service that is appropriate to client's needs. In addition, the potential to save money should always be considered as a second priority to making sure that clients in this population are given every opportunity to have the highest quality of life possible.

CONCLUSION

From the research available, it can be concluded that people who are capable of living semi-independently will generally experience better quality of life outcomes than peers with comparable abilities living in a group home. In addition, semi-independent living services can generally be provided in a way that is cost neutral or even cost saving, when compared to clients who are living in group homes. It is worth noting that there are areas of concern, such as the ability of clients to regularly access healthcare or an increased risk of exploitation. This topic offers many opportunities for future research. Studies could examine more directly the change in quality of life measures for people who are moving out of group homes into semi-independent living. Other studies could examine what basic skills are absolutely necessary for semi-independent living. Finally, research should focus on determining which services are most critical for clients living semi-independently, and how they can be provided in the most cost-efficient manner.

Semi-independent services have the potential to offer what can be considered the best of both worlds for many developmentally disabled clients. Clients are given the maximum amount of input and control that is consistent with their abilities, while caregivers and family have the peace of mind that comes from knowing that their loved ones are still the assistance they need, and appropriate supervision if needed. Finally, it offers the opportunity for state governments to continue to provide critical services to this population in a more cost-efficient manner.

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