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#### Adult Independent Living Outcomes for Persons with Autism Spectrum Disorders

Lisa Biddle Dedmore

## Submitted in Partial Fulfillment of the Requirements for the Degree Master of Science in Education

School of Education and Counseling Psychology

Dominican University of California

San Rafael, CA

May 2013

#### Signature Sheet

This thesis, written under the direction of the candidate's thesis advisor and approved by the Chair of the Master's program, has been presented to and accepted by the Faculty of Education in partial fulfillment of the requirements for the degree of Master of Science. The content and research methodologies presented in this work represent the work of the candidate alone.

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#### Abstract

Young adults with Autism Spectrum Disorders (ASDs) may benefit from lifelong residential, independent living. Often residential housing for persons with ASDs, other than those isolated in the family home, is institutional in nature. The purpose of this research is to identify aspects of a specially designed supported living residence, based on a new co-housing model, referred to in this study as SWSP.

Current research suggests that residents who meet the eligibility criteria will positively benefit from this intentional living environment by virtue of its design. There is one major component to this research. Move-in data was collected from the prior, primary caregiver and the ensuing primary caregiver once the study participant has moved-in to the co-housing residence.

Intake data was gathered from a simultaneous representative survey of parents and initial caregiving staff for the in-residence young adults with ASD. Resident participation in the project referred to, in this paper, as SWSP and participation in any of the independent housing activities formed the study group.

Resulting research data indicates that individuals with an autism diagnosis have diverse needs and exhibit wide-ranging capabilities. The literature and research articulates that highly trained staff and autism specific design features may be most efficacious in addressing the everincreasing adult ASD population.

#### Chapter 1 Introduction

#### Introduction

While working as a research assistant at the Center for Autism, Dominican University School of Education and Counseling Psychology, the Associate Dean, Dr. Rande Webster was approached by the founding board members of the facility addressed in this paper, to discuss a research partnership. After several months of meetings to refine the focus of the research, it was decided that I would facilitate the project.

#### Statement of Problem

Families struggle to provide appropriate long-term care for their aging children with Autism Spectrum Disorders (ASD). It is known that individuals living with an ASD need services from a multitude of agencies to adequately address their needs as they age. Parents often lack the resources and, for any number of reasons, worry what will happen to their children, as they are no longer able to care for them.

#### Purpose Statement

The purpose of this research is examine the effects of adult independent living outcomes by measuring social activity, daily living skills, communication, incidence of maladaptive behavior, and general happiness as evidenced by various data assessment protocols. The key question for this research is to provide answer to, where will individuals with ASDs live as they enter adulthood?

#### **Research Questions**

The research examined whether the adult independent living outcomes listed below, for persons with ASDs, may be enhanced while living in a cohousing model, such as the one setforth by the SWSP:

- 1. Social interaction how can it be optimized within the living environment?
- 2. Daily living skills will they improve given the right circumstances?
- 3. Communication can it be enhanced by virtue of housing design?
- 4. Incidence of maladaptive behavior can they be reduced for those who exhibit such behaviors?
- 5. General Happiness can it be improved for person with ASDs?

#### Theoretical Rationale

For adults with ASDs, dealing with the world and its people can be challenging and can dissolve into misunderstanding, stress, anxiety, and what appears to many as eccentric reactions. Housing providers and architects need to know how best to create autism-friendly environments and how residents can be helped to manage in their homes and their wider communities. Optimal design and neighborhood selection at the outset can help avoid later problems that may necessitate a subsequent move, which could prove debilitating for these residents who need stability and consistency in their lives (Ahrentzen, Barger, Blackbourn, Bosworth, Gerhardt, Hannah, Harris, Oakes, Resnik, & Steele, 2009).

#### Assumptions

The assumption is that in a specially designed residential setting residents will improve their social interaction skills and therefore, social interaction will increase. Maladaptive behavior will decrease. General happiness will increase. It is also thought that communication will stay the same or increase. No assumption has been made about the outcome regarding nutritional data.

#### Background and Need

An estimated 56,000 people in California, with autism spectrum disorders (ASD) become adults every year (California Department of Education, 2012). The cost and complex web of services needed to care for these individuals can be overwhelming for families. Research shows that ASDs are pervasive in impact and affected individuals typically need help from multiple health care and service providers to address various needs (Shattuck, Wagner & Narendorf, 2011). For these reasons, and others, parents often struggle to adequately care for their children on a daily basis. Additionally, parents are often concerned about the long-term care needs, as they and their children age.

#### Chapter 2 Review of the Literature

#### Introduction

This review of prior research provides an understanding and evaluation of the housing models widely available to adults on the autism spectrum. It also addresses the quality of life generally offered in those respective settings. To date, there is ample research providing detailed information on the various housing models currently available. However, until recently there was little focus as to the quality of life each of these housing models provided. Historical context is discussed first, along with a review of the previous research provided by university and autism coalition reports.

#### **Historical Context**

The research provided by Renty and Roeyers (2006) shows that compared to other individuals with intellectual or developmental disabilities in state service systems, people with ASD were, as a group, more likely to live in their family home than in independent or group home settings, and were less likely to experience personal choice and control in major life decisions. They go on to say that while outcomes for adults with ASD have been consistently poor, research has also revealed that one of the most significant indicators of quality of life for individuals with ASD is the quality of supports and services they receive.

The study included fifty-eight high-functioning adults with ASD. The results of their multi-linear regression analysis reveal that support characteristics are related to quality of life in adults with ASD, whereas disability characteristics are not. These results reinforce the significance of an available supportive network; the importance of a substantial needs assessment and effective professional support (Renty & Royers, 2006).

#### Review of the Previous Research

In January 2010, the Department of Developmental Services (2008), the California Department of Finance (2013) and the California Department of Education (2012) published data confirming that the prevalence of ASDs are increasing at an alarming rate. Their collective data indicates that as of January 1<sup>st</sup>, 2010 there were a total of 7,691 persons over the age of 21 with an identified ASD. The same research also showed that there were 41,197 persons under the age of 21 with an identified ASD. These data show a startling differential from 21 years and under vs. 21 years and over. While the general population of California has remained stable since 2000, the population of persons with an identified ASD has increased, on average, about 23-25% over the same span of time (California Department of Finance, 2013). The national increase in persons with ASDs is also estimated to be approximately 23-24% (Centers for Disease Control and Prevention, 2012). Reasons for the population increase notwithstanding, the issues surrounding these increases remain central to the discussion of parents, caregivers, county and statewide agencies that must provide care for these individuals. In addition to the ASD population increase, these data highlight the central question of this research: where will these people live as they enter in to adulthood and how will an already burdened social service system accommodate the complex web of care, required to care for them?

According to the national non-profit group Autism Speaks, the prevalence data are continuing to trend upward, with one in every 88 children (and 1-54 boys) diagnosed with some form of ASD (Robison, 2013). The increase in ASD diagnoses highlights the need for high quality, accessible services and supports that extend across a lifespan. Historically, such services and supports have been both vital and costly. It is estimated that approximately \$35 billion is spent annually on both direct and indirect supports for people with ASD and their families (Ganz,

2007). The available, yet limited, research suggests that the lifetime cost of supporting an individual diagnosed with ASD ranges from \$2.5 million to \$4.4 million per person (Ganz, 2007). Approximately 60% of these expenditures are estimated to be related to adult services and without modifications to the current systems, the significant expense associated with supporting people with ASD is expected to rise in coming years (Gerhardt, 2009).

In an exploratory study of family support services in Massachusetts, three focus groups were convened to obtain the perspectives of parents caring for individuals with developmental disabilities and living at home (Freedman, and Boyer, (2000). In the same study, over a decade worth of research consistently shows that community living for people with disabilities, such as ASD, and their families need person-and-family centered services tailored to individual and family needs and strengths. Supports must also be customized to the unique needs of the individual with ASD with a balance of accessibility and flexibility to meet the changing, diverse needs of the individual and the family (Freedman & Boyer, 2000). Their research highlights that, it is often difficult for families to provide adequate services to their ASD children, maintain other family obligations, care for other members of the family while generating a steady income to maintain a functioning household.

With this level of diversity among ASD populations, it is critical to recognize that people living with autism have a wide range of needs and challenges that impact their housing preferences and needs and that those needs will very often change over time (Pennsylvania Bureau of Autism Services, 2010).

In 2008, the PA Department of Public Welfare's Bureau of Autism Services appointed the Housing Options Committee and charged them with the task of identifying and assessing the housing options that meet the varying needs, preferences and abilities of adults living with autism spectrum disorder (Pennsylvania Bureau of Autism Services, 2010).

There is a very wide range of skills and needs among adults with autism, and their housing needs change over time as they move through different developmental stages. Further, one of the underlying principles of the committee was to maximize housing choice. For some individuals, this may entail renting an apartment and receiving assistance with scheduling or bill paying. For others, it may entail creating a new housing opportunity such as a housing cooperative supported with service providers on a person-centered basis. Yet, for others, this may entail moving to a campus community with on-site staffing. In any case, attaining one's choice requires not only education in housing options but also a comprehensive housing needs assessment and plan for implementation (Pennsylvania Bureau of Autism Services, 2010).

Although individual characteristics can vary widely there are certain traits consistently shared among all persons with ASDs. For instance:

- Many have difficulty with social skills, which often result in feelings of frustration, depression or anxiety
- Many autistic persons are unable to communicate through speech or have very limited speech capabilities, which can also leads to frustration
- Deficits in social awareness such as flexibility and the ability to understand social cues often make residing with others a challenge

- Persons with ASDs can be vulnerable in the community because of their lack of environmental understanding as well as the public's lack of understanding regarding their unique behavior
- For the same reasons as above, this population can also be at increased risk for law enforcement interaction due to lack of understanding of sometimes very challenging public behaviors
- Lastly, many persons with ASDs have both cognitive and sensory issues. Additionally, many may also have co-occurring mental health and medical needs that can greatly impact on their housing setting

According to Pennsylvania Bureau of Autism Services (2010) these unique characteristics create special housing needs and give the following examples as ways to potentially meet those needs. People living with autism may need:

- Support in finding and maintaining housing and also in the coordination of services at their housing site
- Extra space or amenities to accommodate their needs and preferences such as their own bathroom, special lighting or noise barriers as well as an office for 24/7 staffing
- A secure location or security features to minimize risk from traffic and other hazards
- Living arrangements that are flexible enough to meet changing needs over time and life cycle
- Access to public transportation

It is further recommended in the Pennsylvania Bureau of Autism Services research that the criteria for housing selection be based on the above specific characteristics but also include the following criteria:

Housing models must be:

- Affordable to the target population
- Flexible
- Attractive to the individuals living there
- Utilize existing housing options
- Utilize available community resources
- And lastly, are ideally simple, replicable and easily administered

Unfortunately, what the research tells us is often quite different from what many families and persons with ASDs experience. There are many factors contributing to this, mainly the diverse needs and abilities exhibited across the wide spectrum of persons with autism. There is little research showing the prevalence of adults with autism, including a lack of systematic information of where and how they live as adults. One exception is a study undertaken by Easter Seals, Inc. (2008) that included questions about young adults, younger than 30 years of age but having finished high school, which reveals that most young adults with ASDs live with their parents, approximately 80%, more than double that of young adults without special needs (Easter Seals, Inc., 2008).

The other two factors contributing to the deficit in adequate and appropriate housing. They are the rapid rise in aging ASD populations and the financial burden that often accompanies the groundswell of need (Biddle Dedmore, Feb. 2011 – unpublished manuscript).

The CDC has made public statistical data relating to the increase ASD prevalence rates in the United States. This statistical map shows an alarming trend in less than one decade:

ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252)

Identified Prevalence of Autism Spectrum Disorders - ADDM Network 2000 - 2008 - Combining Data from All Sites.

Surveillance Year	Birth Year	# of ADDM Sites Reporting	Prevalence per 1000 Children (Range)
2000	1992	6	6.7 (4.5 - 9.9)
2002	1994	14	6.6 (3.3 - 10.6)
2004	1996	8	8.0 (4.6 - 9.8)
2006	1998	11	9.0 (4.2 - 12.1)
2008	2000	14	11.3 (4.8 - 21.2)

As these data show, 1 in every 88 children (Robison, 2013) born in this country in the year 2000 will have been diagnosed with an ASD by the age of 8 years. Individuals with an ASD had average medical expenditures that exceed those without an ASD by \$4,110-\$6,200 or 4.1 to 6.2 times greater per year. Also, according to the CDC data, in 2005, the average medical costs for Medicaid-enrolled children with an ASD were \$10,709 per child, which was about six times higher than costs for children without an ASD. In addition to medical costs, intensive behavior interventions for children with ASDs cost between \$40,000 to \$60,000 per child per year. The costs for specialized funding and support services for youth and adults with ASD have not kept pace with the increasing numbers of persons being identified as having ASD and in need of services (U.S. Govt. Accountability Office, 2006).

There are consistent data revealing that persons with ASDs have a clear path to services during childhood and adolescence however, the service use among young adults shows a sharp decline in the years immediately following high school. Shattuck, et al.

(2011) conducted a five-year study of post high school service use among young adults with ASD. His primary objective was to produce nationally representative population rates of service use among young adults, aged 19-23, with autism spectrum disorders during their first few years after leaving high school and to examine correlates of use. In his report, Shattuck stated:

We reported on the prevalence and correlates of service use among a nationally representative sample of post-high school youth with ASD. Rates of service use ranged from a low of 9.1% for speech therapy to a high of 41.9% for case management. These rates are lower when compared to estimates for high school students with ASD from the first wave of the same study, six years earlier, when all youth were still in high school: 46.2% received mental health services, 46.9% had medical services, 74.6% were getting speech therapy, and 63.6% had a case manager.\_The estimates are not perfectly comparable because the post-high school sample does not include all the youth from the first wave, as some had not yet exited school and some were lost to follow up. Nonetheless, the differences clearly support the general conclusion that exiting high school is associated with a steep drop in service receipt (Shattuck et al., 2011, p. 5).

Appropriate housing options are one way an individual may receive continuity in services. As evidenced in this research, ASDs are and continue to be an expensive disability to accommodate. States have been challenged to develop comprehensive, well-coordinated systems to support individuals with ASD (Jabrink & Knapp, 2001). The mounting population of youth and adults with ASD are leaving school with substantial support needs which serves to increase the demands on the already stressed adult service system (Hall-Lande, Hewitt, & Moseley, 2011).

It is estimated that over the next 15 years, more than 500,000 Americans with autism spectrum disorders will enter in to adulthood, based on the rising incidence of the disorder. With an estimated 80% of those adults living in the family home, often being cared for by aging parents, who in most cases will not outlive their children (Ahrentzen et al., 2009), there is a need for immediate, viable long-term housing solutions for these people, housing that addresses the complex web of services often needed by this fragile population.

Currently, there are several housing models available. In the following section availability, access to support services, and trends in perception as it relates to each housing model, are examined.

The research shows that while numerous housing models exist, there are significant barriers to individuals successfully obtaining the housing of their choice. The barriers include: difficulty in accessing accurate information about housing and services; the scarcity of resources for creating new housing and the need for expertise in affordable housing development: and the characteristics of some adults with autism that require specific planning and housing design considerations (Pennsylvania Bureau of Autism Services, 2010). Meyers also says, "all of housing models identified have been options for adults with disabilities, but not necessarily for adults with autism, as there have been very few housing options developed specifically for this population" (p.3).

#### Summary of the Previous Literature

From the review of the previous research on the topic of adult independent living outcomes three major themes emerged, 1) advantageous housing models for persons with ASDs, 2) a continuity of services is vital for those persons with ASDs transitioning to young adulthood, 3) the intentional design of housing, specific to those on the autism

spectrum to benefit their overall social, emotional and daily interaction outcomes as they grow in to adulthood.

#### Advantageous Housing Models for Persons with ASDs

Until the 1980s, adults with ASD who did not live with family members, like those with other intellectual and developmental disabilities, were primarily served in public and private institutions and larger group homes certified as Intermediate Care Facilities for the Mentally Retarded (ICF-MR) and funded as optional service under states' Medicaid programs (Hall-Lande et al., 2011).

As large facilities, such as the Agnews Development Center built in 1885 (State of California, 2012), began to close for a variety of reasons through the 1990s and early 2000s, a non-profit housing developer HCS, endeavored to bring major innovation to housing for people with developmental disabilities in the State of California. Between 2006 and 2009, an unprecedented collaboration of public and private agencies, with HCS serving as master developer, created 60 homes in 19 communities specifically designed for individuals from Agnews (Ahrentzen, 2009). A key feature of these newly formed housing developments was that once completed, ownership was transferred to a nonprofit owner, and a service provider leases the opportunity to provide services in the home. This ensures that that the homes remain available for the developmentally disabled population in perpetuity and allows for a higher level of care, as the service provider is separate from the property owner (Ahrentzen, 2009). We discuss the importance of service providers and care in the next segment.

However, this housing innovation for persons with disabilities began to give way to further innovations in housing for persons with ASDs in particular. In the Opening

Doors study, the researchers recognize that people with ASDs and related disorders need lifelong living options that respect and support their rights, individuality and future. Furthermore, all residential models should provide a secure, respectful and nurturing environment. The purpose of their study was to support and clarify the national dialogue on the issue. They identify three areas of classification of housing models including the following: (1) Services in the home; (2) funding for services and the home; (3) the home design and building type. Lastly, the study authors explain that programs and services are critical components of all housing for special populations regardless of funding and design (Ahrentzen, 2009).

Continuity of Services Vital for Persons With ASDs Transitioning to Young Adulthood

The majority of an average life span unfolds in adulthood. Life course theory posits that the few years immediately following the age that students typically exit from high school is a pivotal time for all youth. A positive transition creates a solid foundation for an adaptive adult life course pathway. A negative transition can set the stage for a pathway fraught with developmental, health, and social difficulties. Youth with ASD are especially vulnerable during this period because of their challenges with communication and social interaction, greater reliance on others for aid, and high rates of comorbid health and mental health problems (Shattuck et al., 2011).

Specialized funding and support services for youth and adults with ASDs have not kept pace with the increasing numbers of persons being identified as having ASD and in need of services. Further complicating this issue, there appears to be a significant shortage of trained professionals and specialized services – to meet the diverse needs of individuals with ASD (Hall-Lande et al., 2010). This shortage of specialized services and well-trained professionals to

support people with ASD creates significant challenges for adults in accessing the full range of services they need to live independently in community settings (U.S. Govt. Accountability Office, 2006).

Intentional Design of Housing and the Effects on Social, Emotional and Daily Interaction

The homes and neighborhoods where adults with ASDs live impact the quality of their lives. Yet many housing providers, developers, and architects are unfamiliar with how residential design factors and neighborhood amenities affect these residents' well being.

According to a comprehensive study known as, Advancing Full Spectrum Housing (Ahrentzen, 2009), the following bullet points highlight the intentional design applications that research shows should be present in all housing designed for persons with ASDs, to ensure optimal health and well-being:

- Ensure safety and security
- Maximize familiarity, stability & clarity
- Minimize sensory overload
- Allow opportunities for controlling social interaction & privacy
- Provide adequate choice and independence
- Foster health and wellness
- Enhance dignity
- Ensure durability
- Achieve affordability
- Ensure accessibility and support in the surrounding neighborhood

The Advancing Full Spectrum Housing (Ahrentzen, 2009) authors explain that designing for

a wide range of needs, with a focus on accommodating the issues that occur most frequently such as sensitivity to noise, demand for personal space and the tendency toward physical exuberance, may be sufficient for most residents. They also note that, the design considerations grew out of the case study research into current housing models for individuals with autism spectrum disorders as well as extensive research in therapeutic interventions and findings in the sciences that address autism and the environment (Ahrentzen, et al., 2009).

#### Summary

Overall, in order for housing to appropriately meet the diverse needs of persons with ASDs, thought, planning and attention needs to be given to ensure that residents have an opportunity to live to his or her highest potential. The previous literature indicates a positive trend in the direction of understanding the complex and diverse needs of ASD populations. However, the research and funding issues to provide appropriate housing and support services are overshadowed by the rapid numbers of persons with ASDs transitioning in to adulthood, limited federal, state and local resources and largely ill-equipped service personal. The SWSP may play an integral role in establishing a life-long housing model capable of meeting the needs of this vulnerable and dynamic population.

#### Chapter 3 Method

The method used for this research is both quantitative and qualitative in design.

Administered to both primary, parental caregivers and in-resident caregivers were the Vineland II, Adaptive Behavior Scales (Vineland), the Social Communication Questionnaire, Current form (SCQ), the Children's Communication Checklist-2\* (\*for verbal respondents only, CCC-2), and the General Happiness Scale. All instruments were administered simultaneously and 2 were evaluated for this sample. The two that were evaluated for this sample, were the SCQ and the General Happiness Scale. In addition to the quantitative data, anecdotal evidence is provided to distinguish subtle deviations in the data.

#### Sample and Site

SWSP is a new model, developed after years of traveling to look at existing residential settings, consulting with regional experts in the management and support of individuals with autism, and running focus groups of parents of autistic children. Specific design features were incorporated in order to accommodate the sensory and behavioral challenges of this population. The study's long-term objectives are to determine whether this model is appropriate and effective. To the extent that changes should be made, the study would like to identify what they are. To the extent that that the study demonstrates success with this co-housing model, the goal would be to replicate the relevant features of this model in order to serve the greatest possible number of adults affected by an ASD, throughout California and across the nation.

The research methodology evaluated at time of intake 1) measures of independence, 2) leisure skill development, 3) frequency and quality of social interactions within the household, with

other members of the SWSP community, and with the local community at large, and 4) incidence of maladaptive behaviors. Residents acted as their own control group, necessitating assessment at entry into SWSP. Resident baseline data was collected by the researcher at move-in assessment instruments were completed by parents and caregivers, either in-person or in private.

There is greater community benefit in advancing the discussion of appropriate residential options for this population. The potential risk to participants is that of intrusion in privacy, as well as time in filling out surveys. To that extent, the researcher limited the duration and intensity of direct observation periods, and confidentiality of study participants was maintained at all times. All SWSP families were strongly requested to participate, but there was no discrimination based on lack of participation, nor on honest answers to survey questions.

#### **Ethical Standards**

This paper adheres to ethical standards in the treatment of human subjects in research as articulated by the American Psychological Association (2010). Additionally, the research proposal was reviewed by the Dominican University of California Institutional Review Board for the Protection of Human Subjects (IRBPHS), approved, and assigned number #10062.

#### Data Analysis Approach

Initial data has been utilized to substantiate the current research describing the unique and vast differences among needs, for persons with an ASD diagnosis. Based on the intake assessments data graphs have been generated, examining differences among the resident

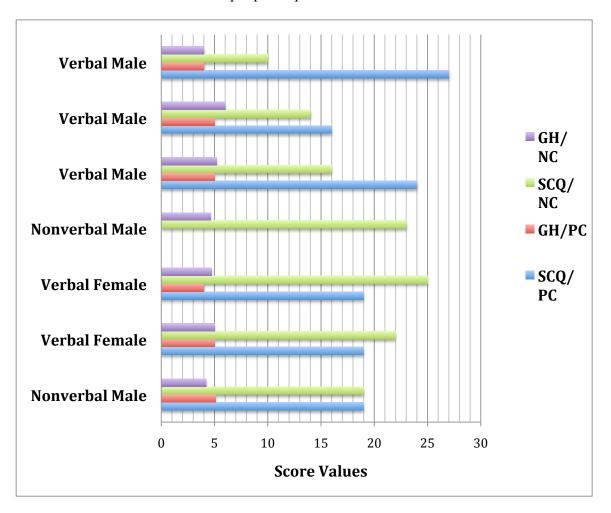
population. The data graphs highlight the diversity among individuals despite their similar diagnosis.

#### Chapter 4 Findings

Description of Site, Individuals, Data

At this point in the research, the entire sample population includes two adult females and five adult males, all of which have a clinical diagnosis of autism. Of the two adult females, both are verbal. Of the five adult males, 3 are verbal and two are non-verbal.

Identical data was collected from all sample participants.



The above graph represents a portion of the data collected from the initial seven sample participants. GH/PC = General Happiness Primary Caregiver. SCQ/PC = Social

Communication Questionnaire/Primary Caregiver. GH/NC = General Happiness/New Caregiver. SCQ/NC = Social Communication Questionnaire/New Caregiver. A primary giver is defined as the primary parent caregiver of the sample participant, prior to move-in. A new caregiver is defined as the sample participants, primary caregiver after move-in. One resident's parent caregiver data was unavailable at the time of printing.

Although all participants are adults with an autism spectrum disorder, either verbal or non-verbal, their abilities and needs are quite diverse. On the high functioning side of the spectrum were both a male and a female participant that function independently in the community, attending junior college and vocational training, respectively. Additionally, there were both male and female sample participants that were semi-independent and capable of self-direction. On the lower functioning side of the spectrum, there were two male sample participants that require one-to-one, twenty-four hour, side-by-side care.

#### Overall Findings, Themes

Despite having a diagnosis of autism and relatively similar scores in the areas of general happiness as well as social communication, the sample population of seven, shows great diversity in personal care needs. There is no way to adequately offer group support personnel, group job or training services or even group housing to address the various needs individuals with ASDs. Each individual with an ASD diagnosis is an individual with unique needs and support requirements.

#### Chapter 5 Discussion / Analysis

#### Summary of Major Findings

The research literature clearly articulates that service use among persons with ASDs sharply declines after leaving high school. Housing models are most closely aligned with this drop in service use. As stated in previous pages, approximately 80% of adults with an ASD live at home with aging parents. Traditionally, it has been very difficult for parents and existing housing models to account for the diverse needs of those on the autism spectrum. These facts, combined with inadequately trained caregiving staff, account for society's inability to properly address the serious crisis posed by the rapid increase in the adult ASD population.

Research data indicates that by creating a stimulating, socially diverse community in which the residents have individual, unique and specific, highly trained caregivers, the needs of each SWSP adult resident are accounted for, in ways that are previously unseen. As each resident has his or her own team of caregivers, in addition to familial support and community support, many of the issues seen in past housing models (steep drop in service use, inadequately trained caregiver personnel, etc.) have been addressed. By taking in to account the deficits of all previous models, the SWSP co-housing model should support the diverse needs of adults with an ASD.

#### Limitations/Gaps in the Study

The research literature contained limited data on the type of co-housing model studied in this paper. The co-housing model under review in this paper was an amalgamation of the leading research heretofore untested. Therefore, the current research bases it suppositions in advance of any quantitative data.

The present study was limited in scope. Only seven of the sixteen residents were included in this preliminary research and only two of the four assessment protocols were used as comparison measures.

#### Implications for Future Research

There are several implications for future research. Future research needs to identify quantitative data results at the conclusion of this eighteen-month study. Additional research should include a financial feasibility study to determine the ability of states, municipalities and or, non-profit groups to replicate promising aspects of this model. Lastly, there is valid need for a socio-economic, demographic research study to be conducted based on barriers to entry regarding a co-housing option such as the SWSP.

#### Overall Significance of the Study

Residents will benefit from a full range of services and daily, social interaction. The SWSP co-housing model continues to evolve, meeting the diverse needs of an ever-increasing adult ASD population. Caregiver training will improve by continually examining and implementing the new data, bettering the entire caregiver community. Families will be given a

reprieve in the daily demands of caring for their adult children, therefore having better outcomes than if their adult child had remained in the home.

#### About the Author

The author has been a special education teacher in various public school settings.

Currently, she owns her business working with children in need of highly individualized behavior and instructional support. She became interested in researching adults on the autism spectrum after working as a staff research assistant at Dominican University. While completing her Master of Science degree in special education she was asked to work on a two-year research project that seeks to quantify adult independent living outcomes as a result of residing in a highly intentional co-housing community. The preliminary findings of this research are contained herein.

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