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## What Makes a House a Home? Supported Living Environments for Adults with Autism Spectrum Disorders

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Running Head: What Makes a House a Home?

**What Makes a House a Home?**

Supported Living

Environments for Adults with Autism Spectrum Disorders

By

Rose Meadows

A culminating thesis submitted to the faculty of Dominican University of California in partial fulfillment of the requirements for the degree of Master of Science in Education

San Rafael, CA

May 2018

## What Makes a House a Home?

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

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**Abstract**

My research aims to address how supported living environments for adults with Autism Spectrum Disorders (ASDs) can best support their stakeholders. This is an inherently human and personal problem, but existing research tackling this problem utilizing a person-centric and/or resiliency theory lens or framework is lacking. My research will use the perspective of parents/guardians and staff/caregivers in combination with existing knowledge and research to create ideas for how to maximize support in supported living environments for adults with ASD and their families. This is a qualitative study that uses a humanized approach and in-person interviews with stakeholders to highlight their perspectives and understandings. It was found that there was a great deal of internal and external tension for stakeholders, both within themselves and in relationships with each other. Examples of these tensions include: providing care vs. promoting independence; professionalism vs. friendship; and self-actualization vs. assimilation. These tensions pushed stakeholders to explore and evaluate difficult topics which must be addressed in order to have a truly supportive living environment. The implication is that supported living environments should provide opportunities to air these tensions and explore their roots, leading to productive conversations, greater cohesiveness, greater trust, and more individualized supports.



### **Acknowledgements**

I would like to thank Dr. Urbani for her mentorship and accompanying me on this academic journey. I would like to thank Dr. Lucko for her understanding of the scientific process. My most heartfelt thanks go out to the families and individuals who opened their homes and stories to me.

## Chapter I: Introduction

Sarah<sup>1</sup> felt lost. She felt desperate. She had travelled almost 2,000 miles in the hope of an answer, only to fail to find one. She was out of options, so she made one herself.

Sarah is one of a rising number of people: a guardian to an adult child with Autism. Sarah wanted, like many parents, to assist her child in developing a greater feeling of self-esteem and independence by living outside of their family home. Sarah was also getting on in years, and wanted to have the comfort of knowing her child would be safe and settled, even if she passed on unexpectedly. Sarah didn't want it to be left to her other children to sort through the bureaucratic mess of safety-proofing a house, choosing and paying for appropriate care-providers, facilitating social and employment opportunities, and otherwise ensuring that Sarah's daughter, Summer, was happy, fulfilled, and living a good life. Sarah felt out of options, so she made one of her own. She worked with other parents in her same situation, and together they founded their own model of supported living for their adult children with Autism Spectrum Disorders (ASDs). That supportive living environment became a home called Sunrise.

Sarah and Summer's story, however, is all too common. At the time of this writing, the San Francisco Autism Society had recently concluded its annual conference (2017), where the theme this year was housing. The story of many speakers had striking

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<sup>1</sup> All names –both of people and locations/residences- presented in this paper are pseudonyms to protect anonymity.

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*similarities: My child was diagnosed with Autism. My child started to grow up. My child needed a place to live that supported them in their growth and independence, and that I could trust to care for my child when I am gone. I couldn't find that place.* Diagnoses of Autism Spectrum Disorders (ASDs) are increasing exponentially, and many children with ASDs are now adults who find themselves no longer able to access many of the support services that were available to them during their school years through the Individuals with Disabilities Education Act (IDEA). According to the Centers for Disease Control (CDC), a diagnosis of an ASD was found for approximately 6.7 people per 1,000 children in 2000. Since that time, the rate of diagnoses has more than doubled. In 2012, approximately 14.6 children per 1,000 had a diagnosis of an ASD. Put another way, in 2000 an estimated 1 in 150 children were living with a diagnosis of an ASD, but twelve years later the rate of diagnosis had jumped to an estimated 1 in 68 children having a diagnosis of some kind of ASD. This sharp spike is the subject of much debate. Regardless of the cause or reason behind this, the facts are that this is a population that is increasing, and the services required to support this population need to increase with it.

According to The Arc<sup>2</sup>, an organization dedicated to individuals with intellectual and developmental disabilities (I/DD), one contributing factor to the housing shortage for those with I/DD is the increasing age of many of their guardians. Approximately 38%

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<sup>2</sup> The Arc was founded in 1950 as a grassroots organization by family members of people living with I/DDs, and allies from the community, and was a key force in the passing of inclusive legislation such as the Americans with Disabilities Act, the Education for All Handicapped Children Act, and the addition of disability as a protected category under the Fair Housing Act.

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of those living with ASD are also living with a diagnosis of an I/DD (Center for Autism Research, Children's Hospital of Philadelphia, 2016). The frequency of a concurrent diagnosis of an I/DD amongst individuals with an ASD makes this information relevant to a consideration of living environments for those with Autism. Furthermore, supported housing is not always exclusive in terms of disability served, and can frequently be designed to serve people with multiple and different disabilities, including both ASD and I/DD. The case example supported living site studied in this research project, for example, began as supported housing for those with ASDs or ASD and I/DD, and is now considering becoming a supported housing option for individuals with ASDs, I/DDs, or both. Existent research has explored issues related to specialist housing for those with I/DD and comparing that with housing options for those with I/DD and ASD comorbidity (Felce, Perry, Lowe, & Jones, 2010).

It is neither accurate nor feasible to begin researching housing options for a certain population without also considering broader, holistic issues of what makes a home and a high quality of life, as well as what struggles and stereotypes the population in question has experienced in some prior research attempts. In the literature regarding supported living for people with Autism, there has historically been a focus on achieving traditional life goals or outcomes, such as being employed, marrying, having a family, and avoiding institutions (Henniger & Taylor, 2012). Research more directly related to housing has included specific housing models, questions to guide guardians in assisting their child in the choice of living environment, as well as guidelines for professionals

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embarking on designing a supportive housing complex (Doenyas, 2016; Lowe, Gaudion, McGinley & Kew, 2014; Lubestky, et al., 2011).

Lowe, Gaudion, McGinley & Kew, in their guidelines for designing supported living, advocated a more person-centric view. They felt that such an orientation was essential to best support the individual residents. Intervention research also advocates for a person-centered view in order to best support and satisfy individual wants and needs (Tobin, Drager, & Richardson, 2014).

Much like a person-centric lens, the resiliency lens attempts to consider the whole person and their particular wants, needs, and situation. However, the resiliency lens also emphasizes that successful outcomes for individuals are facilitated by the presence of certain personal characteristics and environmental factors that can increase “resiliency.” The resiliency lens advocates using a more strengths-based, positive perception of the person in their individual entirety, as opposed to focusing exclusively on areas of need (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016; McCrimmon & Montgomery, 2014). This is in keeping with person-centered planning, a recent trend in educational philosophy that seeks to empower those with disabilities and their families by offering them greater voice in the process of planning for their education and other needs (Rasheed, Fore, & Miller, 2006). The focus, it is argued, must be on the individual and their unique needs, wants, goals, and strengths, not the system or institution providing services, including education.

Person-centered and resiliency lenses take a more whole-person and holistic approach: they help us step back from numbers and societally imposed traditional

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“outcomes,” and examine an individual’s life in a way that honors their individuality and is closer to their own perspective. However, it can be difficult to approach more holistic questions in a scientifically rigorous way. How and when can we deem someone happy, or describe them as living a happy life? How can a researcher appropriately conceive of, address, and measure quality of life? Happiness can be considered in the moment or over a broader length of time, and with a greater or lesser focus on physical, bodily satisfaction (Feldman, 2010). Cultural factors also impact considerations of happiness (Oishi & Gilbert, 2015). Quality of life theories exist at the intersection of philosophical and psychological research. Quality of life research is well-populated with sub-theories that focus on specific areas of additional intersection, such as quality of life and aging, quality of life and medicine, quality of life and disability, quality of life and gender, etc. (Nussbaum & Sen, 1993). These theories provide a way of considering what is important in a life, particularly in a setting or situation where the person concerned may not always be making the decisions for themselves, given conservatorship or other methods of guardianships.

One such item of importance in a person’s quality of life is social integration (Nussbaum & Sen, eds, 1993). Researchers have considered the question of friendship as a social concern, a quality of life concern, and even a matter of biology (Brent, Chang, Garièpy, & Platt, 2014; Chen, Bundy, Cordier, Chien, & Einfeld, 2016; Tobin, Drager, & Richardson, 2014; Jamil, Gragg, & DePape, 2017; Poon, Koh, & Magiati, 2013). People with ASDs can report high levels of loneliness, and are more likely than neurotypical peers to report not having a friend (Friedman, Warfield, and Parish, as cited in Scheeren

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& Geurts, 2015, pg. 5). Peer groups are one way proposed for those with ASDs to form friendships, as are social skills interventions (McCrimmon & Montgomery, 2014).

Mediated social experiences and opportunities to interact long-term with neurotypical peers are other suggestions for how to increase ability to form and access to friendships for individuals with ASD (Doenyas, 2016).

However, some researchers have argued that for members of the Autistic community, friendship isn't as important or desirable as it may be for those outside of the Autism Spectrum (Jamil, Gragg, & DePape, 2017). That said, friendship and social skills are consistently rated as highly important amongst guardians and caregivers of those with ASDs (Poon, Koh, & Magiati, 2013; McMahon & Solomon, 2015).

Furthermore, studies created with the direct input and participation of those with ASD (such as in-the-moment questions texted to participants) indicated enjoyment and engagement with social matters (Chen, Bundy, Cordier, Chien, & Einfeld, 2016; Tobin, Drager, & Richardson, 2014).

Research can, at times, leave the goals of stakeholders behind: in the United Kingdom, families and stakeholders in the Autistic community felt that much of the research taking place did not look into practical matters that were relevant and of use to them (Pellicano, Dinsmore, & Charman, 2014). This is one problem that resilience lens and person-centric informed research has tried to highlight and address by calling for further research that treats the community the research is meant to serve with respect and as a partner in learning. The Autistic community and its allies are comprised of diverse individuals, with equally individual needs and strengths. Any researcher who

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wishes to participate in the research process with the community should honor these individual elements and aspects, as well as the voice of the community. Therefore, having listened to stakeholders, the questions driving this research are designed to have a more practical bent. The aims of this research are to create information and research that can be understood and used, not just in the academic realm, but by real people, in real situations, facing really tough real-world decisions.

Another area this research hopes to address lies within quality of life research. While research into happiness and quality of life is extensive, there is a benefit into examining the intersection of quality of life with specific demographic information, particularly of vulnerable populations. This is evidenced by research into areas of quality of life such as quality of life and gender, quality of life and aging, and quality of life and disability. Therefore, this research strives to contribute to the literature addressing quality of life and disability—specifically quality of life and ASD.

This research attempts to use person-centered and resilience lens informed practices and philosophies to look into this intersection of quality of life and ASD. This study aims to provide information that will be of immediate significance to the site used as a case example regarding the supports they provide their residents and stakeholders. This research also has relevance to educators, because considering how to best support the quality of life of an adult with Autism is an extension of special education principles and duties. Supports for children and young people with ASDs often begin to fade away or disappear entirely as those individuals ‘age out’ of the school system and are no longer covered by the Individuals with Disabilities Education Act (IDEA). For special



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educators, particularly those in high school or otherwise dealing with students of an older age, part of their job is to prepare students for this transition out of school, as it can be a very fraught and difficult time for individuals with special needs and their families. Where and how a young person is going to live is a crucial element of this process: Will this person live at home? Will they be living outside of the home? Is the residence permanent, or is there a different long-term plan or goal? What level, and type, of support will this person need to have a good quality of life wherever they are living? It is vital to determine how to help families navigate these very important and often emotional and difficult decisions regarding their own and their child's future. My primary research aim is to empower community members and stakeholders to make informed decisions about what's best for themselves and their families.

This is a subject close to my heart. In keeping with the guidelines for humanizing research as put forward by Django Paris and Maisha T. Winn (Humanizing Research, 2014), rather than defining myself as an objective researcher removed from the situation and context I study, I am seeking to engage in a project that will give voice to vulnerability and be of use to the community. I want to work *with* those involved in my project, treating them with respect and partnership in shared learning and benefit, rather than treating them as objects of research. Related to this concept, person-first language is used throughout this paper. Person-first language is tied into many of the same concepts that form the foundation of person-centric theories. Linguistically,

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person-first language brings the focus to the individual over their diagnosis, difference, or other descriptor.<sup>3</sup>

I strive for this project to provide an honest and human set of practical tools and information regarding housing for adults with ASDs. I hope to be a part of my participants' ongoing journeys, and to continue to hear of their successes and struggles. I hope that this project will help provide some sense of that "immediate, practical use" found to be lacking in existing research (Pellicano, Dinsmore, & Charman, 2014, pg. 760).

This study's primary form of data is interview data. Interviews were conducted with multiple stakeholders, in an attempt to create meaning through conversations with multiple perspectives. Family members--guardians of adult residents with ASDs at Sunrise--were interviewed. Caregivers employed at Sunrise were also interviewed to provide another perspective. It is hoped that multiple perspectives will be able to provide a deeper understanding than any one perspective would. In line with person-centric theories of research—as well as personally important to my own approach to research—this study aimed to include the direct perspectives of individuals with ASDs.

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<sup>3</sup> There is some arising debate over person-first language. Some people and groups, including the Autistic Self-Advocacy Network, argue that it stigmatizes Autism. It is suggested that person-first language belittles people's Autistic identities. Autism, it is argued, is an inseparable part of a person's identity that should be validated with primary placement, like other identities, such as ethnic identities or sexual orientations (Brown, 2011). It is beyond the scope of this paper, and beyond my right to comment as a non-Autistic person, to attempt to answer this debate, however the multiple perspectives must be acknowledged. It is not the intent of this author to invalidate anyone's identity, nor to contribute to the stigmatization of Autism. The choice to use person-first language reflects the person-centered framework adopted by the author, and an attempt to value and respect the individual.

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The Autistic Self Advocacy Network<sup>4</sup> (ASAN) has adopted the slogan “Nothing About Us Without Us” (Autistic Self Advocacy Network, 2017). This is a crucial point to consider when conducting research with a community, and heavily informs the research approach adopted. Unfortunately, unrelated and unexpected health concerns prevented those residents with ASD at Sunrise who wished to participate with this research from being interviewed within the time constraints of this study.

On-site observations were also conducted. These observations allowed for researchers to develop rich, thick description of sites (Geertz, C., 1994; Ponterotto, J., 2006). This description will include available facilities (such as for social activities, personal interests, or physical fitness), overall appearance, and sensory features (including colors, lighting, and sound). Other data to be taken under consideration during this research project include site records, Individual Program Plan (IPP) data, Individualized Service Plan (ISP) data, and prior interview records. These records will provide more information and therefore a better depth illustrating that site, and a useful case study. This research is a part of a broader research project regarding Sunrise headed by Dr. Urbani at Dominican University.

The primary findings of this study are that the emotional lives of stakeholders and their relationships with each other play a strong role in their experience of supported living environments. In particular, stakeholders experience interpersonal and

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<sup>4</sup> A 501-c nonprofit organization “...run by and for autistic people” with a focus on public policy, grassroots advocacy, community education, self-advocacy, and disability rights. (<http://autisticadvocacy.org/about-asan/>)

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intrapersonal tensions regarding the difficult decisions they have to make. These tensions often stem from simultaneously holding two opposing ideals, and the resulting “push and pull” between them, such as a parent wanting the most growth and best possible life for their adult child, but also wanting their adult child to develop and demonstrate independence and exercise their right to make their own choices in their own life. Stakeholders—residents, their families, and staff-members—could also experience tension in their relationships with each other when they had differing opinions regarding how to answer these difficult questions, and balance these opposing ideals. One additional finding was the importance of supported living environments facilitating friendships for residents, including caregivers and staff taking on a more friendly role with residents. A second additional finding was the value of shared spaces built into the construction and design of supported living environments for adults with ASD. Lastly, the physical location of the supported living environment was found to be important, in the sense that it needed to provide for easy access to the community to facilitate community integration and participation.

The implications of these findings are that supported living environments can best support stakeholders by facilitating opportunities to air and explore these tensions, and build trust and rapport amongst stakeholders. Conversations and perspective-taking can allow for the acknowledgement of feelings, improved relationships, and the productive construction of a third space that allows for better, more-informed, decision making that addresses multiple inputs and perspectives on these difficult decisions and issues. Supported living environments can also facilitate belonging through social and

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community engagement, through social skills training, the facilitation of social opportunities and friendships, including a friendly role from staff-members and caregivers, dedicated shared spaces within the supported living environment, and a location that allows for easy physical access to the local community.

## Chapter II: Literature Review

By focusing on practical supports that can help people live their current life to its fullest, this research explores an area of study under-researched in the field of ASDs. Krahn and Fenton (2012) found that only 4% of global research into ASDs in the period of 1996-2000 related to “family and services” with 94% of research focusing on “pillar I and II concerns,” which are broadly biomedical and clinical<sup>5</sup> (Krahn & Fenton, 2012, p. 298). While these are understandably a high priority for the research community, they do not address the immediate needs and wants of stakeholders in the Autistic community and their allies. These community members are described as less interested in the origin of Autism, and more so in how to best support themselves, their child, or their friend with ASD (Pellicano, Dinsmore, & Charman, 2014).

In order to shape the discussion regarding supported living environments for individuals with ASDs, I will first discuss quality of life research to provide insight into the philosophical and psychological concepts of happiness. Most people want to be happy, and quality of life research can provide the intellectual tools needed to address this important topic in a rigorous way.

Secondly, I will explore person-centric theories of research and resiliency lens literature, as these inform the philosophical frameworks and lenses that will provide the heart and structure of my research. A person-centered resiliency lens leads us to focus on each person as a whole--with their own goals, struggles, successes, and interests.

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<sup>5</sup> It should be noted here that these biomedical and clinical concerns did include some interventions research, which made up 20% of the 94% along with symptoms (52%), causes (18%), and diagnoses (4%).

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This emphasis on the individual is more respectful and humanizing when researching a community of which one is not personally a member, and which has experienced bigotry and ableism. Thirdly, I will explore the importance of personal or special<sup>6</sup> interests, in working life, social life, and play. For many people with an ASD, personal interests can be a very strong force for joy in their lives, and to be a path towards socialization opportunities, employment opportunities, and a greater sense of self-esteem (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016; McGonigle, Handen, & Lubetsky, 2011; McCrimmon & Montgomery, 2014).

Fourthly, I will consider social opportunities. The mechanics and reality of social integration for individuals with ASDs are too-often ignored (Doenyas et al., 2016; Scheeren & Geurts, 2015). Friendship is often a high priority for the parents of a person with an ASD (Poon, Koh, & Magiati, 2013). There is conflict in the literature regarding the topic of friendship, as experienced by individuals with an ASD. Some researchers suggest that individuals with ASDs have less interest in friendships and/or enjoy and prioritize them less than neurotypical peers (Jamil, Gragg, & DePape, 2017). In contrast, other researchers have concluded that individuals with ASDs have interest in and enjoyment of friendships, and argue that data suggesting otherwise may reflect social anxiety and difficulty with social skills rather than a disinterest in or distaste for friendship (Tobin, Drager, & Richardson, 2014; Chen, Bundy, Cordier, Chien, & Einfeld, 2016). Social skills interventions are therefore often recommended practices as a

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<sup>6</sup> Special interests are sometimes also called “obsessions” or perseverative behaviors, but this article will use the description of ‘personal’ or ‘special’ interests in the interest of avoiding a potentially pejorative term.

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support for individuals with ASDs. Studies have found that these peer groups can also provide a social outlet, self-esteem benefit, and sometimes even friendships amongst the individuals attending (Doeniyas, 2016; McCrimmon and Montgomery, 2014). Some studies have found that many individuals with ASDs found the chance to engage with other Autistic peers positive (McCrimmon and Montgomery, 2014), whereas others suggest that it is necessary to engage socially with neurotypical peers to develop social skills and achieve positive social outcomes (Doeniyas et al., 2016).

Finally, I will consider opportunities for employment and daily activities. Daily activities are essential to a good quality of life. Employment is associated with higher self-esteem and independence, as well as creating social opportunities (Tobin, Drager, & Richardson, 2014, McGonigle, Handen, & Lubetsky, 2011). As full or even partial employment is not always a feasible goal, daily activities are an essential support that can provide some of the benefits of employment while being more accessible to some people (Scheeren & Geurts, 2015).

### **Quality of Life and Happiness**

Quality of life research provides the foundation for initial considerations about housing options for individuals with ASDs. It aims to examine how to take in the full scope of someone's life, and tackle the difficult question of what *is* a good life. Quality of life measures are crucial to understanding the effectiveness, supportiveness, and appropriateness of a housing environment. It can be difficult to measure something so ephemeral as an individual's quality of life, but it is often comprised of elements such as happiness, success, independence, belonging, and health. Sen (1993) writes that well-



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being is comprised of a plethora of “functionings” including “...elementary ones [such] as escaping morbidity and mortality, being adequately nourished, having mobility, etc., to complex ones such as being happy, achieving self-respect, taking part in the life of the community, [and] appearing in public without shame” (pg. 37).

It is a cliché that many parents, when asked what they want from and for their child, will answer “I just want them to be happy.” In fact, parents frequently rate personal happiness as one of the most important future outcomes for their children (Poon, Koh, & Magiati, 2013). Happiness is essential to quality of life. Henniger and Taylor (2012) emphasize this point during their discussion of how to weigh and consider outcomes in an individual’s life. They do this by asking whether it is accurate to consider someone as experiencing a positive outcome if they are employed without thought of if they are *happily* employed or not. In other words, is it a good life to have a good house and a good job, or do those things need to produce good feelings in order to authentically be a good outcome?

Philosophy and psychology researchers frequently examine the notion of happiness. Exploring ideas of happiness is an important part of any discussion about supported living environments informed by person-centric and resiliency lenses. Do the supports offered provide what the individual residents need to be happy in their unique lives? Additionally, happiness is important to consider when adopting a resiliency informed lens, as feelings of happiness increase resiliency, and therefore positive outcomes (McCrimmon & Montgomery, 2014).

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### Happiness

Happiness can be elusive, and difficult to possess or define. Philosophy provides ways about thinking about this broad concept to make it easier to define. Psychological research brings these concepts back down to earth with statistical and cultural information that allows for greater accuracy in discussions and conceptions. Crucially, psychological research tackles cultural matters in the conception of happiness and success.

Feldman (2010) advances a theory of personal happiness he calls Attitudinal Hedonism about Happiness (AHH). Contrary to the Dionysian cliché perhaps conjured by the word “hedonism,” AHH conceives of happiness as something beyond the physical, and has a person-centered focus when considering happiness. Attitudinal Hedonism about Happiness states that to be happy is to be *more happy than not* in any given moment, period of time, or lifetime. This does not mean not experiencing negative emotions; it is rather a question of the weight of them. Feldman gives the example of a new mother to help illustrate this point. She may be experiencing great physical pain, tiredness, and perhaps anxiety about tackling her new role. However, despite all this, many mothers still experience a feeling of overwhelming joy on the occasion of their child’s birth. The idea that happiness or joy do not necessarily exclude negative feelings is important to bear in mind when considering the appropriateness of certain supports and activities in supported living environments. For instance, Chen, Bundy, Cordier,

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Chien, & Einfeld (2016) found that while many so-called “higher functioning<sup>7</sup>” individuals on the Spectrum reported high levels of anxiety during social events, they did not report that they would rather be alone. Social anxiety may, therefore, affect friendships or other social events and relationships for those with an ASD, without actually meaning that socializing is an unhappy event. The unhappiness of social anxiety can co-exist with the happiness of social connection, as indicated by being alone *not* being considered preferable to being in company, despite the presence of anxiety.

Oishi & Gilbert (2015) define a happy person as “...a person who has pleasant feelings most of the time, and feels satisfied with his/her life overall” (pg. 54). Crucially, these authors also bring attention to the cultural elements of happiness, pointing out that different communities and cultures have different perceptions about happiness. For many individuals participating in American culture, the authors argue, the emphasis on the pursuit of happiness—the idea that everyone can create happiness for themselves through hard work, an active lifestyle, material gain, etc.--can cause individuals to actually reduce their own happiness by reducing socializing and other happiness-providing events and activities.

In addition to socializing, the authors identified positive self-esteem was as a key element and predictor of happiness in American culture. Other researchers (Tobin, Drager, & Richardson, 2014, McGonigle, Handen, & Lubetsky, 2011) have found that

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<sup>7</sup> This is the terminology used in the cited research, so it is emulated here for the purposes of accuracy. Some in the Autistic community, however, can find this sort of phrasing offensive, preferring ‘significantly affected by Autism’ to ‘lower-functioning’ and ‘less significantly affected by Autism’ to ‘higher functioning.’ (Autism Society San Francisco Bay Area [SFASA], 2017).

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employment or daily activities (such as morning music or exercise, volunteer opportunities, hikes, crafts, chores, etc.) can increase feelings of self-esteem. Therefore, when considering quality of life in supported living situations, it must be remembered that employment assistance and/or scheduled daily activities have been found to increase self-esteem, which in turn is associated with happiness, a cornerstone of a good quality of life.

Supportive housing cannot be said to be truly supportive if it only ensures a resident's survival, and not a minimum standard quality of life. Research supports that emotional needs are central to overall quality of life (Nussbaum & Seds, 1993). As friends, family, allies, and members of the Autistic community, it is crucial that we hold ourselves and providers to a high standard of support, in order to ensure that adults served are able to have an appropriate quality of life. To be truly supportive, supported living must support the whole person: mind and body. Henniger and Taylor (2012) argue that it is inauthentic to consider someone as having a good life if they are not, to put it simply, also having a good time, or being happy. A productive outcome meeting traditional measures of success, such as employment, is not the same as an outcome that indicates a truly happy individual.

Lastly, supporting residents' quality of life and happiness increases positive feelings for their family as well. Poon, Koh, & Magiati (2013) found that one of the future outcomes most highly valued by parents for their child was their child's happiness. Happiness is individual and affected by culture, but can be supported through the development of individual's self-esteem through concrete procedures,

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including employment, daily activities, and social opportunities (Oishi & Gilbert, 2015; Tobin, Drager, & Richardson, 2014; McGonigle, Handen, & Lubetsky, 2011).

**A Focus on the Individual:**

**Resiliency Theory, Person-Centric Theories, and Personal or Special Interests**

Research has shown that a more person-centered perspective that honors and utilizes the special interests and talents of those with ASDs increases self-esteem and opportunities, particularly for social interaction (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Higher self-esteem and more frequent opportunities for social events and daily activities are associated with happiness, belonging, and quality of life (Tobin, Drager, & Richardson, 2014; Oishi & Gilbert, 2015; McGonigle, Handen, & Lubetsky, 2011). Furthermore, quality of life is inherently personal, therefore it can only be accurately addressed using a person-centered lens (Tobin, Drager, & Richardson, 2014). Resilience research looks into those factors and characteristics that help a person deal with the ups and downs in life. It also advocates taking a strengths-based perspective when addressing the wants and needs of individuals and populations. Resilience theory advises addressing areas of need while simultaneously shining a light on areas of strength. This approach considers a person more holistically, personally, and authentically. This shift in orientation can increase self-esteem, outcomes, and relationships between service-providers and those receiving services (McCrimmon & Montgomery, 2014).

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### **Resiliency and Person-Centric Theories**

The Autistic Self Advocacy Network (ASAN) argues that there should be “Nothing about us, without us” (ASAN, 2017). This principle of *nihil novis* fits in well with the credo of a person-centered orientation, as it emphasizes learning about the individual, their experiences, and gaining meaning from and through them. Essentially, it advocates building outwards from the individual, rather than imposing a grander concept and applying it to every individual. Every person is a unique individual who has their own traits, preferences, circumstances, and history, all of which affect them, and their life, as well as how others perceive, interact, and respond to them. Person-centered orientations seek to explore and honor the uniqueness of the individual and their life, and, in that way, dovetail well with a resilience theory framework.

Resilience theory examines those characteristics that allow individuals to have resilience. Resilience, in this case, means their ability to ‘bounce back’ and recover—even grow—from struggles. Any one individual may have an assortment of beneficial and potentially negative characteristics in their situation and environment, as well as personal behaviors, that affect their ability to withstand the storms of life.

A crucial intersection between resilience theory and special education is an emphasis on strength-based approaches or perspectives. Inclusive special education philosophy and the neurodiversity movement are shifting the focus from the deficit-based model of special education to instead highlight the strengths of a student served, as well as considering areas of need (Armstrong, T., 2017). Resiliency lens -informed

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practices regarding those with special, or different, needs advocate for this same strengths-honoring treatment in both research and services. Together, resiliency and person-centered informed lenses bring the focus to the individual, what strengths that individual possesses that can be tapped in order to help them continue to grow, and what supports they as an individual need in order to withstand and thrive in an often uncertain and challenging world.

Personal or special interests can be a source of great strength for individuals with ASD. The honoring, sharing, and exploration of personal interests amongst a group of peers or caregivers has been found to increase trust and self-esteem (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Teti, Cheak-Zamora, Lolli, & Maurer-Batjer (2016) took a resiliency theory informed lens to their study on the use of Photo-Stories amongst young people with ASDs. In Teti, Cheak-Zamora, Lolli, & Maurer-Batjer's (2016) research, they work to create a photo-stories series with small groups of young people with ASDs. First, these young people were given a camera and instruction on how to use it. They later returned to the group with a photograph that encapsulated a part of themselves, story, or interest they wanted to share with the group. The opportunity to share personal interests and to connect with others on this level had social benefits for the participants according to the research (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Participants also expressed finding great joy in their special interests, both engaging in them in general, and in having opportunities to share them. Furthermore, other Photo-Stories research as cited in this article (Teti et al., as cited in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016, pg. 628) found that there was a humanizing effect

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to projects that increased positive feelings/connections and trust between caregivers and residents. This is relevant to supported living environments for adults with ASDs because supported living environments also rely on an interplay between residents and caregivers or service-providers.

In Teti et al.'s research, they utilized the same type of project as in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer (2016)--a Photo Stories project--but with a different population: patients with HIV/AIDS, who then shared their Photo Stories with hospital staff. Sharing something so personal as the Photo Stories was found to help increase relationships and connections between patients with HIV/AIDS and medical staff. The Photo Stories offered the groups studied (both HIV/AIDS patients and young people with ASDs) a chance to celebrate and display something personal. Teti et al. found that the sharing of these artistic works fostered greater interpersonal relations and trust between resident and caregiver (or service provider) in a living environment--a hospital, in that case--in addition to the goal of increasing medication adherence. Photo-Stories projects, therefore, are an example of an activity that supported living environments for those individuals with ASDs should consider, both for the building of interpersonal relationships and trust between resident and caregiver (as found by Teti et al., as cited in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016, pg. 628) and the social benefit of positive relationships amongst project participants with each other (as identified in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer's research).

The principles of communication and the sharing of personal interests also apply to the physical design of supported living environments for those with ASDs (Lowe,



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Gaudion, McGinley & Kew, 2014). Researchers stress the importance of communicating with residents regarding their personal & special interests, and then making sure that the living environment provides residents with ample opportunities to engage in those interests. Lowe, Gaudion, McGinley & Kew interviewed residents and created a 'tree' of residents' interests, which was a visual representation of residents' interests, grouped by similarities (the leaves on the different branches). The housing designers were able to utilize this tree to best ensure that the living center provided adequate and appropriate facilities so that residents could explore, engage with, and share their special interests. One example was creating a garden with space for both private escape and enjoyment as well as larger spaces for shared physical activities, such as tai chi or yoga. Game rooms, galleries, libraries, activity rooms, and clearly labeled social spaces are all other examples of ways to accommodate and encourage the pursuit of special interests in supported living environments, as well as the social benefit the exaltation and exploration of these special interests can provide for individuals with an ASD.

Special interests can also be at the heart of matters of employment for adults with ASDs. McGonigle, Handen, & Lubetsky, (2011) advocate that service-providers work with the people in their care to help them find employment that is related to their special interests. Employment is crucial for self-esteem (McGonigle, Handen, & Lubetsky, 2011). Relevant to a discussion on personal or special interests, however, it is important to note that integrating someone's special interests into their employment allows said employment to be more accessible, appropriate, and engaging. In short, employment that dovetails with someone's special interest or interests will be more

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likely to be interesting, and therefore help encourage their success and personal satisfaction in work. Special interests, in this way, can provide structure and motivation for social and professional relationship building and engagement.

In addition, other research advocates for the encouragement and exploration of special interests not just as a way to access employment, but also social groups and feelings of greater self-esteem (McCrimmon & Montgomery, 2014). Special interests provide a point of shared reference and interest, a topic of conversation, and a way for individuals with ASDs to be presented as an expert, which allows those individuals to enter a social situation from a position of strength. For instance, if somebody is knowledgeable about airplanes, a travel club or group of flight enthusiasts would be somewhere where that person could share that interest, have conversations about it, meet others with a similar interest, and be perceived as an expert. Rather than being an outsider, this would be a place where this person could be celebrated for their knowledge and enthusiasm. This is crucial, given the importance of friendship to quality of life. Given that young people with an ASD are more likely to report not having a friend as compared to their neurotypical peers. Thus, this is an area that merits focus when trying to design or choose a living environment that supports best quality of life for individuals with ASDs (Friedman, Warfield, and Parish, as cited in Geurts and Schereen, 2015, pg. 5).

A person's particular interests and joys can—and should be—emphasized and supported by the activities and architecture of a supported living environment. Personal or special interests can provide a framework for social opportunities, engagement in

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work or employment opportunities, and a happiness all of their own (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Supported living environments can be structured in such a way as to encourage the perusal and sharing of these interests, allowing for higher quality of life and more social opportunities (Lowe, Gaudion, McGinley & Kew, 2014). Staff in supported living environments can assist residents in seeking out activities or employment related to their interests, allowing for more engagement and social benefit (McCrimmon & Montgomery, 2014). Participants in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer's (2016) Photo-Stories project self-reported increased happiness and self-esteem from the opportunity to engage with and share their interests. The individual interests of people with ASDs can provide myriad opportunities, practically and personally, and provide increased happiness and quality of life, when explored and shared.

### **The Importance of Belonging: Social Bonds Including Friendship and Community**

Social bonds and community are essential aspects to culture and human development. Theories even suggest that our minds developed out of a need to keep track of members of our community and our various social bonds (Brent, Chang, Garièpy, & Platt, 2014). These social bonds are crucial to our overall quality of life. Tobin, Drager, & Richardson (2014) suggest that a deficit in social skills is often the root cause of many elements reducing quality of life for those with ASDs, such as in the arenas of friendships and employment, and advocate for opportunities to build upon and develop social skills and also to help increase quality of life. Community involvement is a broad collection of social bonds that has also been cited as an element

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necessary to quality of life (Nussbaum & Sen, 1993). There is a pleasure to belonging and to engaging with those we perceive as like us, in one way or another. There is also a pleasure to feeling like we are a part of a community, like we belong. This can be evidenced in responses from participants with ASDs in social research who have indicated a social benefit to participating in group discussions with peers with ASDs (McCrimmon and Montgomery, 2014). In these group discussions, individuals with ASD expressed positive feelings regarding the chance to interact with others on the Spectrum. However, forming social bonds with a more diverse group can teach us, help us grow, and connect us to an even broader community. Friendships increase our quality of life, as do other social bonds, such as family and the broader community. Social bonds can even arise from employment or other work or daily activity opportunities, such as volunteering.

Research suggests that peer groups and interventions provide a social-emotional and skill benefit to those with ASDs (Doeniyas, 2016 and McCrimmon & Montgomery, 2014). McCrimmon & Montgomery (2014) found that those individuals with ASD participating in the studied peer group interventions expressed enjoyment when given the chance to socialize with others with ASD. Participants reported that interacting with peers who also had an ASD was a positive outcome of the intervention groups for its own sake, beyond any skill benefit of the intervention. One participant was quoted as saying “Just being able to be with people who have similar traits as me [sic] boosts my self-esteem,” and another that, “I found myself thinking on more than one occasion, ‘thank god [sic] I’m not the only one,’” (pg. 391). Doeniyas (2016) also put forward a

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proposed social benefit (socialization opportunities) of the chance to interact with peers with ASD, though the author also heavily stressed opportunities for interaction with neurotypical peers.

Parents and guardians highly value their child with Autism having a friend (Poon, Koh, & Magiati, 2013). When ranking the relative importance of various skills, the parents of those with an ASD are more likely to place a higher level of importance on many social skills when compared to how their children with ASD ranked the importance of those same skills (McMahon & Solomon, 2015). Parents of children with Autism also report lower incidences of their children with ASDs engaging in or displaying social skills than their children self-report (McMahon & Solomon, 2015). One social skill in which both parents of children with ASDs and their children indicated similar levels of importance and engagement to each other was cooperative skills. This lead McMahon and Solomon (2015) to identify cooperative skills as a potential area of strength in terms of social skills for those with ASDs. It is, however, important to note when considering this data that parents may be unaware of the extent of their children's social engagement with peers or misunderstand what is considered appropriate for a different generation in terms of social behavior and skills (McMahon and Solomon, 2015). This means that, despite the discrepancy, the social skills and engagement self-reported by the participants with ASD may not be less accurate than that reported by their parents.

Disagreement in results is not restricted to results reported by parents and their children, however. Friendship is a controversial topic in the literature. Some studies argue that those with ASDs value friendship less highly and find it less enjoyable or

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essential to quality of life than neurotypical peers (Jamil, Gragg, & DePape, 2017). It may, however, simply be more difficult for those with ASDs to initiate and maintain friendships: biological examinations of the roots and neurological elements of friendship have suggested that Theory of Mind (ToM) – the desire and ability to understand the wants and feelings of others – is essential in the development of friendships. Certain base skills such as the ability to follow eye-gaze and determine and recognize individuals as well as their relationships and friendships with each other are also crucial ‘building blocks’ that must be established before friendships can be easily forged (Brent, Chang, Garièpy, & Platt, 2014). Initiating and following eye-gaze can be difficult for some people with ASDs (Nation and Penny, 2008), which may be a possible root of some social difficulty for individuals with ASDs.

Like any skill, however, theory of mind skills can be developed. Research has shown that individuals with ASDs who have an older sibling often demonstrate stronger theory of mind skills than peers with an ASD and no older sibling (Brent, Chang, Garièpy, & Platt, 2014). It is speculated that this may be because of the social practice interacting with a peer. Older siblings can help model social skills and can often serve as an “automatic” friend for their younger sibling with ASD. Of course, social skills modeling and practice opportunities can only develop social skills if this modeling is observed and noted, and these opportunities are utilized. If it is speculated that the presence of an older sibling allows for stronger theory of mind skills through social access or opportunities, that assumes that the younger sibling with ASD is engaging in social activities with said older sibling. If there is engagement with social opportunities and

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activities, there must perforce be motivation for them. Struggles in the development of friendships does not mean a lack of desire for them, nor a lack of authenticity in those friendships formed. Interviews, in-the-moment questionnaires, and other qualitative data created *with* those with ASDs indicate that friendship is valued, being alone is not always preferable, and that while there may frequently be skill deficits in the ability to initiate and sustain friendships, and anxiety surrounding social situations, there is indeed a desire for friendship and personal connection (Tobin, Drager, & Richardson, 2014, Chen, Bundy, Cordier, Chien, & Einfeld, 2016). Therefore, it cannot be assumed that individuals with Autism do not enjoy, pursue, or value friendships without silencing their own voice.

## **Community**

Friendship, however, is not the only type of social connection: community belonging is also central to quality of life. Community integration is an important goal for many (Scheeren & Geurts, 2015; McGonigle, Handen, & Lubetsky, 2011). Communities provide support, identities, and opportunities for socialization, exploration, activities, and employment.

What does it mean to be a part of a community, however? Scheeren & Geurts (2015) define community integration as having occurred when someone "...has something to do, somewhere to live, and someone to love" (pg. 1). In considering this it must be remembered that there are many ways to love. Not everyone is interested in a romantic or sexual relationship. It is, however, very human to want some kind of

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positive relationship--whether that love be between friends, family, a romantic partner, or some combination.

Supported living environments can assist in the pursuit of social integration for their residents by providing opportunities to engage with others and the community. Structured social opportunities can allow supported living environments to assist in the development of “someone to love,” as well as somewhere to live. As discussed previously, peer groups and social skill building events can provide a crucial avenue towards personal and social connections. These social connections are important steps towards community integration.

Community integration and participation is not, however, an entirely clear-cut issue. Some advocate for the fullest integration possible, with active participation in community events (Scheeren & Geurts, 2015; McGonigle, Handen, & Lubetsky, 2011). However, Tobin, Drager, & Richardson (2014) put forward a slightly different vision of time in the community. “[p]articipation in the community need not involve social activity to be meaningful...” (p. 216). In other words the researchers are arguing that there is a quality of life benefit to individuals with ASDs accessing the community even when that community activity is not a form of social interaction. This argument is one that addresses an issue of accessibility. It still stresses involvement in the community, while allowing room for scheduled activities that aren’t necessarily social in nature. Social activities may prove too difficult or anxiety inducing for some, perhaps emotionally or perhaps logistically. For instance, a community event may not have the support needed to allow access for non-verbal individuals. Examples of non-explicitly



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social, but still communal events, that may be more accessible for some individuals are: visits to parks, community clean-up events, drum circles and dinners that are open to the community and participating in the local farmer's market. During these events, participating residents may elect to interact socially, but the option to participate without talking is an option.

A third group of researchers, however, argue that social opportunities in the community are not enough. Doenyas (2016) suggests that social opportunities in the community need to be mediated and supported by professionals in order to be fully actualized. The importance of integration into a social network that includes neurotypical members is also heavily stressed. In contrast to Doenyas (2016), other researchers have found a self-expressed benefit to interaction with Autistic community/peer groups (McCrimmon & Montgomery, 2004) and non-mediated social opportunities (Chen, Bundy, Cordier, Chien, & Einfeld, 2016).

Social opportunities are multifaceted and bring about myriad kinds of benefits. For instance, chances to share personal stories and insight (through a Photo-Stories project) forged greater inter-facility community trust and relationships (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). Social opportunities, therefore, not only build social skills and possibly create and lead to friendships, increasing quality of life and resiliency, but they can also help build trust and familiarity between residents and staff serving them (Teti et al., as cited in Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016, pg. 628).

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Supported living environments have other unique ways they can facilitate and encourage social opportunities and a greater sense of community within the facility. By designing and building living environments so as to create community spaces that are customizable for comfort and specific needs of those with ASD--such as clearly labeled spaces with multiple types of seating, dimmer-switch lighting, etc.—it is possible to increase access to social opportunities in a way that respects the needs of some individuals on the Spectrum (Lowe, Gaudion, McGinley & Kew, 2014). This point is supported by Sicile-Kira & Sicile-Kira (2012). These authors acknowledge the fight for complete inclusion, and that everyone has a right to be fully included in the community, while reminding us that some members of the Autistic community support communal living situations because of sensory accommodations (such as preferred or calming colors, and noise reducing construction and materials), as well as a more understanding attitude regarding potential absences from social events or a need for time alone.

Humans are social creatures (Brent, Chang, Garièpy, & Platt, 2014). We enjoy meeting people who are like us (McCrimmon & Montgomery, 2014). We value friendship highly enough that it is very important to us to know and trust that our loved ones have a friend in whom they can confide, or otherwise take comfort (Poon, Koh, & Magiati, 2013). The chance to socialize and engage with a friend or forge a friendship is valuable enough to us for us to risk the social anxiety that can often go hand-in-hand with that process (Chen, Bundy, Cordier, Chien, & Einfeld, 2016). More broadly, being socially connected within our communities as well as with our individual friends is essential to quality of life (Nussbaum & Seds, eds, 1993). Community integration is an

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important goal for advocates and researchers alike (Disability Rights California, 2016; Geurts & Schereen, 2015; McGonigle, Handen, & Lubetsky, 2011). Supported living environments can encourage the development and pursuit of social bonds and opportunities through activities—including daily activities, employment, and community activities, professionally facilitated or not--, skill development and peer groups, and the architecture and environment of the residence itself—including clearly labeled group spaces that are sensory-safe.

### **The Importance of Purpose: Employment and Daily Activities**

One of the main ways people engage with their community and develop a social group is through employment (McGonigle, Handen, & Lubetsky, 2011). Furthermore, employment is associated with higher self-esteem (McGonigle, Handen, & Lubetsky, 2011), and greater quality of life (Tobin, Drager, & Richardson, 2014). Self-esteem may seem like a small piece to consider when looking at the whole of a person's life, but self-esteem has been found to be a great predictor of quality of life/happiness in Americans (Oishi & Gilbert, 2015). Employment provides a sense of purpose and feelings of self-esteem (McGonigle, Handen, & Lubetsky, 2011). Purpose and self-esteem then help to pave the way for feelings of happiness, and, ultimately, quality of life. Beyond internal feelings of happiness, purpose, and self-esteem, employment also provides access to the community, and social opportunities (McGonigle, Handen, & Lubetsky, 2011). Furthermore, employment has traditionally been considered a very strongly positive "outcome" according to researchers evaluating outcomes in the lives of those with ASDs (Henniger & Taylor, 2012).

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However, employment is not the only way to achieve purpose. Tobin, Drager, & Richardson (2014) stress the importance of daily activities in relation to considerations regarding employment. While, as stated previously, employment is fundamental to self-esteem, social opportunities, independence, and success for many people, it is not necessarily achievable nor a feasible goal for every person (Scheeren & Geurts, 2015). Neither does it equate to happiness for everyone – employed doesn't always translate to *happily* employed (Henniger & Taylor, 2012). Tobin, Drager, & Richardson (2014) found that there was lower quality of life for those without employment *or other regular daily activity*, and that the inverse was true as well. Essentially, while employment is a great goal, having regular, scheduled, activities that feel purposeful, whether or not one is paid for them, is associated with higher quality of life. Possible purposeful activities could be volunteering, community events, or chores or tasks associated with one's place of living. To ensure best quality of life, it is crucial for people to have something to do with their time (Scheeren & Geurts, 2015).

Truly supported living, therefore, needs to consider the daily activities of its residents. Daily activities, whether or not they are employment, are essential to happiness, self-esteem, and quality of life (Tobin, Drager, & Richardson, 2014; Scheeren & Geurts, 2015; McGonigle, Handen, & Lubetsky, 2011). They provide purpose, social access, and opportunities for growth.

### **Conclusion**

Prior research has shown that opportunities for social interaction/integration, daily activities/employment, and opportunities for the exploration and sharing of

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personal interests are associated with higher quality of life. There are case studies of specific interventions, but what does it look like to create an *environment* that consistently supports and encourages growth in those areas? What *long-term* elements need to be in place to best support the development of quality of life? Research on designing supported environments and policies appears to be much thinner than specific interventions or medical research.

Indeed, while the topics of supports, living environments, friendships, and quality of life have been studied before by many accomplished scholars, articles surveyed for this literature review advocated for increased research utilizing a person-centered and/or resiliency lens, a lens that honors the needs, wants, individuality, and strengths of those with ASDs (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016, Henniger & Taylor, 2012). Furthermore, there is an increasing need for housing options that support the quality of life for those with ASDs, and expansion of services isn't keeping up with expansion of service need (Hewitt et al., 2016, McGonigle, Handen, & Lubetsky, 2011). Research has also found that stakeholders want more practical, usable, information in this field (Pellicano et al., as cited in Scheeren & Geurts, 2015, pg. 2).

My research aims to address the problem of the increasing need for appropriate housing options for adults with ASDs by seeking to develop practical understandings about how to best design adult supported housing. This is an important idea to study as the population with ASDs is increasing, and their guardians are aging, often becoming less able to provide in-home care themselves. The need for housing is rapidly expanding

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beyond current constructed capacity, and as more environments are built to serve as homes for those with ASDs, it is the obligation and duty of service providers, allies, and community members to ensure that these homes are as supportive as possible to best facilitate the quality of life of residents. The purpose of this research is to explore the specifics of supportive housing in a way that embraces an individual-first orientation that celebrates the unique strengths, as well as needs, of the community it serves. To that end, this study examines how to design housing or living environments for individuals with ASDs that best supports residents' quality of life—including their happiness, relative independence, belonging, purpose, and success.

Many of these elements of quality of life are interwoven and support each other. Purpose—employment or other daily activity—increases self-esteem, which is linked to happiness, and fosters social opportunities, which are, in turn, key to a good quality of life. Employment also brings monetary reimbursement which can help with independence and success. Non-compensatory daily activities are nevertheless tied in with skill development and success, which build self-esteem and, ultimately, therefore, quality of life and happiness. In this way, supported living environments must consider the whole of a person's life to best build their happiness and quality of life.

## Chapter III: Methods

### Description and Rationale

The primary question to be investigated by this case example-based research is: how can supported living environments for adults with ASD best support stakeholders, such as residents, their families, and caregivers in advancing their quality of life? A supported living environment may be a group home that is privately run, run by a charity, or the government; or a family home with professional or familial/community network support. Quality of life is a multi-faceted concern, and this research will consider several aspects of quality of life, including happiness, independence, belonging, purpose, and success – both as defined by the self and by legal documents such as an Individual Service Plan (ISP) or Individual Program Plan (IPP).

This study is primarily qualitative, focusing on interview data. Some quantitative data will be used to add depth to this study by examining progress on IPP and ISP documents on a convenience sample of residents at Sunrise.

This research project is informed and inspired by humanized, person-centric, and resiliency lenses in an attempt to ensure that this research (and researcher) is respectful and equitable. Paris and Winn (2014) advocate for being honest about one's humanity and biases, rather than attempting complete objectivity. This perspective allows one's peers and readers to consider what is presented in an authentic, informed, manner. Potential biases, rather than being concealed, are admitted in honesty to allow for greater clarity. It is argued that everyone has some kind of bias – we are all human and

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the products of our circumstances and past. Honesty over potential points of bias, then, allows the reader to be aware of this possible influence, rather than it being hidden.

As a way to move closer to this goal of acknowledged and shared humanity between researcher and participant, Paris and Winn discuss the idea of a dialogic spiral in their writing. In this model, learning and understanding develop as a result of taking turns listening and talking. This model is designed to ‘humanize’ the research process by making it a mutual generation of ideas and progress. The researcher and participant are both part of a conversation with honesty, growth, the development of *shared* meaning, and a certain ‘give and take.’ In my project, I aim to work with my fellow participants, knowledge seekers, and stakeholders with that same sincerity and equity of purpose, utilizing interviews and interactions as a way to gather information dialogically, supplemented and strengthened with observations and a review of existing information and literature.

Sunrise, the case example studied, is situated in Northern California. The “campus” is comprised of a community center, gym, pool, garden, farm, and four shared homes, each with the ability to house four residents each, for a total capacity of sixteen residents. Each home has an en suite room for a care-giver. The buildings are all painted in neutral colors, with accents of gray and warm wood. Arts and crafts created by residents, and community boards that describe available activities, the schedule, and resident and staff-member accomplishments and birthdays, with photos, provide splashes of brighter color. Cement and stone pathways are softened with plantings of plume grasses. They offer an accent of color and mild sound in the wind, but have no



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strong perfume or scent that may cause a sensory issue. Sensory needs were further supported through the use of sound dampening materials during construction and the choice to build high ceilings into each room. Houses face each other, and pathways converge together and guide walkers toward communal spaces in attempts to use the architecture to help support social opportunities.

The Board and residents of Sunrise are mostly White or European-American, and residents are primarily of a higher socio-economic status. In fact, two interviewed members of the board described their disappointment with a lack of diversity in Sunrise's residents. A parent also described her sense that, as a result of this, there was some tension with the local community, some members of which viewed Sunrise as elitist.

## **Design**

This case example research is a small piece of a larger study. The Institutional Review Board accepted the broader research proposal as described by Dr. Urbani of Dominican University, and as implemented by her and graduate student support staff, including myself. Personal information such as ISP and IPP information was examined only with the individual concerned or conservator's consent. Similarly, caregivers were only interviewed with the consent of the individual they serve or said individual's conservator's consent. All participants received a copy of their "bill of rights," and their ability to revoke consent at any time was stressed throughout the project.

Multiple conversations and presentations explaining the project were given to the Board and Parents Committee of Sunrise, with researcher contact information made

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available so that possible participants could have their questions answered and know the purpose of the research as well as who was conducting it. As part of this dedication to transparency and respectful treatment, it was determined that all transcription and coding work for this portion of the research would be conducted by the identified researchers so that information could be controlled, and anonymity preserved.

Due to issues of time, access and privacy, sampling was a combination of convenience and snowball sampling. As many residents/conservators at Sunrise as possible were invited to participate (through presentations and meetings with parent and participant groups, announcements, and email blasts).

### **Methods**

This primarily qualitative study utilized a variety of data collection methods, including interview data, observational data, and IPP/ISP data. The emphasis will be on interview information.

#### **Interview data.**

Paris & Winn (2014) advocate for the concept of a dialogic spiral in order to create meaning with others through discussion. It is argued that by discussing matters as partners, by sharing thoughts and feelings, each person can help the other to meaning, and be creating that meaning mutually, as equals. Using this as a model, strengthened by the importance of 'nothing about us without us,' and the essentiality of partnering with the community, interviews were designed to be flexible and conversational. It is hoped that this increased participant comfort through familiarity and a certain informality and human connection. Secondly, it was further hoped that

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this would encourage partnership - talking *with* community members, rather than *about* them.

Three primary “types” of participant were invited to join us in this research. We wanted a combination of perspectives to try and get the most accurate and in-depth picture of stakeholders’ lives. For this reason, this project included interviews from multiple perspectives, including parents or guardians and caretakers or staff. Adult residents of Sunrise were invited to participate in this research, and two individuals agreed to do so. However, unexpected health concerns in both cases prevented the possibility of an interview. The ongoing nature of these concerns meant that it was not possible to schedule an interview with these individuals within the time period of this research. Information from on-site observations and guardian and caregiver interviews were used to provide some insight into this crucial perspective.

By including and honoring these multiple perspectives on the issue, we hope to be able to develop with participants a deeper understanding of stakeholders’ lives and experiences. Interview questions were open-ended and flexible and responsive to participants’ answers in order to allow for meaning and understanding to be built through the dialogic spiral. These open-ended questions were designed to prompt participants’ positive and negative feelings and experiences regarding Sunrise, such as how they came to work at Sunrise or choose it as a residence for their child, what they most valued about Sunrise, and what they would like to change at Sunrise. Interview questions are available as Appendix A. Interviews were audio recorded and subsequently transcribed and coded by one of three researchers involved in this project.

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There were six interviews in total, and seven participants: four parents and three staff-members. Two parents, a married couple, were interviewed together. All interviews were face to face and ranged from fifty minutes to two hours and forty-five minutes. Interview locations were chosen so as to be convenient and comfortable for interviewees, based on their location and needs. They were selected to allow for both comfort and privacy, and included both a participant's home and a researcher's office.

Interview protocols were informed by a person-centric approach and the dialogic spiral, and therefore took cues from the interviewee in terms of level of formality, and were more conversational, allowing the participant to have an equal hand in guiding the learning and conversation. Given the frequently emotional nature of the discussions, interviewers attempted to use language –both verbal and non-verbal – that created an atmosphere of welcome and safety. Interviewers engaged with interviewees on a friendly, equal, level, per the dialogic spiral. This conversational model was chosen in order to further support participants' emotional safety, as a conversation may feel more familiar and less intimidating than a more formal interview. Interviews used a conversational format with a flexible set of base questions depending on the type of participant –family member of a resident or caregiver. The goal of a dialogic conversation is to listen to interviewees' emotions and experiences and to learn from them, rather than to get answers to particular, specific, questions.

### **Observation data.**

Observation data was conducted in-person at the research site. Rich, thick, description was gathered to best be able to understand the contexts of different environments to readers of the research (Geertz, C., 1994; Ponterotto, J., 2006). Note

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was made of available facilities, overall appearance, and sensory features. Available facilities included questions such as whether or not there was a gym on-site, outdoor areas, pool, kitchen, shared social spaces, or other similar useable architectural elements. Overall appearance included such factors as colors, shapes, decorations, maintenance, and/or existence or lack thereof of positive elements (such as cleanliness, greenery, light, high ceilings, soothing colors), and negative elements (lack of cleanliness, broken items, closed off areas, etc.). Sensory elements of a place of living can have a very strong effect on someone's day to day life, particularly a person with an ASD, who may have environmental sensitivities. Therefore, sensory elements such as the quality of light, and level and type of noise and smell in an environment were stressed in researcher notes. Particular attention will be paid both to these sensory features, and the use (or lack of use) of available facilities (such as gyms, playrooms, and social spaces) and activities (such as communal dinners, on-site communal events like Bingo Night, outdoor excursions such as hikes, or community events such as a day trip into the broader community). Furthermore, as daily activities and access to both social and private spaces are very important, ease of access (or lack thereof) were considered. Ease of access includes physical elements such as clear pathways and clearly marked areas.

### **ISP and IPP data.**

An Individual Program Plan (IPP) is a document designed to serve as a "roadmap" for individuals with special needs, the state, and service providers. It lays out an individual's goals, and the services and support that they need to achieve those goals and increase their independence and community participation (Disability Rights

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California, 2016). A person-centered IPP is to be provided to every “consumer” over the age of three. A consumer is defined as a person eligible to receive services from the regional center, which is in turn defined as a “private, non-profit, agency...under contract with the Department of Developmental Services to coordinate services and supports for persons with developmental disabilities,” (California Department of Developmental Services, n.d., pp. 281). IPP goals are similar to Individualized Education Plan (IEP) goals in the sense that they provide a ‘snapshot’ of a person’s overall progress, focus on areas of need, and are supported with appropriately collected data. IPPs, like IEPs, are legally binding documents. IPP goals often will focus on practical aspects of a person’s daily life, such as a goal about learning how to use mass transportation, a goal about getting out in the community or getting exercise a certain number of days per week, or a goal about learning how to write a resume to increase employment opportunities. Individual Service Plans (ISPs) are documents created by service agencies that outline for staff/caregivers the goals and items and activities of importance to residents and their families. They are created with input from caregivers, residents, and residents’ families, but are not legally binding.

IPP and ISP data was gathered from three residents at Sunrise who personally consented or whose conservators consented to share this information. This data was used to add depth to participant responses, such as by identifying discrepancies in priorities identified during interviews and those reflected in ISP and IPPs and comparing stakeholders’ sense of daily activities or enrichment with the documentation of a residents’ day-to-day life.

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### **Research Positionality**

Inspired by the humanized research philosophy as advocated by Paris and Winn (2014), I do not attempt to claim that I am anything other than a human being, dealing with other human beings. While bias is to be avoided and minimized as much as possible, I, like anyone, cannot claim to be entirely without it. Rather than accidentally hiding that and potentially tainting data by trying to remove the human element of an inherently human project, I would rather be upfront and honest with my background, beliefs, and potential biases, so that the reader can best evaluate my work in as informed a way as possible. While every attempt was made to learn from the perspectives and knowledge of others, I wish to be as clear as possible from the outset regarding any potential biases that may have affected how I heard the conversation. I am a special educator, who has been trained in a program, schools, and agencies that emphasize a strengths-based approach and a personalized approach when creating supports for individuals with special needs. Furthermore, several of my personal friends self-identify as being Autistic or on the Spectrum, and what they have shared with me regarding their personal experiences makes me highly value the importance of respecting the personal choices of those individuals with ASD, rather than prioritizing “typical” expectations or aspirations upon neurodiverse individuals. Through my connection with these individuals, I have been exposed to the neurodiversity movement, and its stresses upon acceptance over assimilation.

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Conversation, dialogue, and open exchanges with others throughout this project were often emotional. The well-being of ourselves, our friends, and our families are inherently emotional topics. Most of us can empathize with the fear for our child's future and happiness, even when they are adults, or understand what it is to feel lonely, or insecure, or isolated. Many of us know the feelings of having too much or too little to do, of "cabin-fever" or, conversely, a feeling of being overwhelmed and wanting to just go home and rest for a while. Quality of life is inherently a very emotional and human topic. Particularly with issues of such an emotional nature, I believe that sharing these feelings as much as possible, trying to listen and be with those sharing their experiences in the moment, can provide both a better understanding of what is being shared, and a more respectful treatment of the participants that acknowledges their feelings and reflects them in a more natural, conversational, communal, and human way.

A researcher participating in the humanizing process is honest about their emotions and experiences, and how that could affect the meaning they create with participants in their research, and the lens through which they view and analyze data. I readily admit that I am emotionally affected and invested in this project. As stated, many of my personal friends self-identify as being on the Spectrum, and I've had dialogue with them regarding their lives and some of the struggles and joys that they've faced and found in different housing environments. Additionally, as a special education teacher, I've engaged with families regarding their concerns for their child's future, and how their child will be equipped to live their best life going forward. I've worked with students to whom I became emotionally attached, and I've worried for their future, and



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the lack of support that many of our young people with differences and disabilities face once they 'age out' out of the school system. I am emotional about this subject, and want my students and people like them to have the support they require to live a full and happy life. The Council for Exceptional Children, of which I am a member, states that it is the responsibility and an essential purpose of education to assist students in becoming "contributing citizens, family members, employees, learners, and active participants in meaningful vocational, recreational, and leisure pursuits," (Council for Exceptional Children, 1997).

Another way I am emotional in my approach to this topic is my connection to Sunrise. Listening to interviews, and interacting with residents and their families, I built an emotional connection. I felt happy to see happiness in them and celebrated their successes. I believe that this emotion does not hamper or hinder my work, but rather enhances it. Emotion is a central component to a life. People's happiness and feelings of success are part of their quality of life, and their sadnesses and struggles diminish their quality of life. Therefore, I believe that sharing feelings in the moment with those participating in this project helps me better understand what residents and their families are feeling and experiencing themselves. Through shared dialogue, emotion, and connection, we can build meaning, knowledge, and understanding together.

### **Data Analysis**

This study's primary data source is interviews. Interviews were recorded electronically, and then transcribed by researchers on the project. Interviews were coded by participant researchers, as informed by prior literature, the goals of this

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project, and discoveries upon the way. Preliminary and exploratory interviews revealed, for instance, that friendship was a key term for which we ought to code.

Researchers used strategies and insights from grounded research, case studies, and ethnographic research to help structure interview data analysis. From grounded research, the team made use of stepped coding and analysis within theoretical frameworks. Researchers also heeded lessons from case studies and ethnographic research, which advocate for the presentation of data within context. Therefore, in keeping with these insights, researchers made note of the surrounding environment during interviews and observations, and used active listening and open-ended questions to be ready to learn of elements and events that have shaped the participants' worlds.

### **Validity and Reliability**

This primarily qualitative study utilized data and perspective triangulation to try and increase the validity of themes and findings uncovered or learned throughout the dialogic process. The perspectives of multiple groups - family members and caregivers – were used to strengthen findings. Triangulation of data was further strengthened by bringing in more data from individual residents' ISPs and IPPs.

Member checking was also employed to increase the validity of themes and the results of this project. Summary information was provided to participants in order to provide them the opportunity for comment, including whether they agreed or disagreed with the findings, and if so, why, and to what extent. While not every participant responded to this request at the time of this writing, the opportunity was provided, and

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all participants who were able to respond responded to the summary of findings positively.

Rich, thick, description was written regarding the site and situations in order to best provide full context, depth of understanding, and validity. The details regarding the design of an environment are what can make it supportive and welcoming, or what can make it simply be a place to live, not to thrive.

Lastly, researcher background and potential biases have been disclosed in order to provide clarity and increase validity. I readily acknowledge an emotional connection to this study. Throughout conversations with individuals whose lives have been affected by Autism – both individuals with ASD and their loved ones – emotions can run high. Anything so immensely personal as someone's home and future will be an emotional topic, and that is what this article aims to explore: what ways the home of a person with an ASD can be best supportive of their quality of life as they go forward into the world and their future.

## Chapter IV: Findings

One of the first things taught in geometry is that a triangle is the strongest shape. Used in everything from great works of architecture such as the pyramids to classic literary tropes like the love triangle, the triangle is everywhere--including sites for supported living. In supported living environments there exists a triangle of relationships: between a parent or guardian of an adult with ASD, the adult with ASD, and the caregivers or staff. These relationships play a crucial role in the development of day-to-day life and decision making at a supported living environment.

Tensions exist both internally for each member of this triangle, as well as in the relationships between members (interpersonal tensions are depicted in Figure 1, attached as Appendix C). Furthermore, this "tensions triangle" is also set into a specific environment, which affects all members of the triangle. For example, parents or guardians feel tension regarding protecting and caring for their adult child with ASD on the one hand, and promoting their independence and growth on the other. Caregivers and staff experience tension regarding "pushing" the person in their care towards traditional concepts and milestones of progress, and acting upon the immediate, perhaps more short-term, goals of the person in their care. Adult residents with Autism experience a tension between assimilating into the broader, more neurotypical, society of the world around them, and the opportunities (social, activities, and employment) that offers on the one hand, and on the other hand, the pursuit of their own internal world, interests, preferences, and existence as a person with an ASD now living in a predominantly Autistic community within a neurotypical world.

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The findings of this study highlight these intrapersonal and interpersonal tensions. Those interviewed expressed their own conflicted feelings, as well as concerns or conflict in relationships with other primary stakeholders. The findings from this study suggest that these tensions and conflicts arise because they are necessary. Much of the tension occurs around very difficult choices for which there aren't always universally "correct" answers. How much should I push my child or this person in my care, and how much should I preserve their day-to-day or in-the-moment enjoyment? How much should I shepherd my child or this person in my care, and how much should I promote their independence? Where is the appropriate place to land between being a professional and being a friend? How much should I try to fit in with the world at large, for social and employment opportunities, and how much should I be me, no matter the consequences? None of these questions are easy.

Those interviewed explored these questions with us, and their personal tension and conflict regarding them, but—as these are questions without easy or obvious answers—very few of those interviewed felt that they had found the answer. All of these questions require thought and consideration. Tension regarding these questions allows for that consideration and deeper thought. Being pulled in these different directions, feeling these different impulses, makes individuals think about where they are and if it is where they ought to be. In supported living for adults with ASDs, tension and conflict—both interpersonal and intrapersonal—was evidenced by participants on a continuing basis. Those interviewed would come back to these tensions and crucial questions, continuing to think about them and how to resolve those tensions and answer the

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question at multiple points in their and their adult child's life. As many of these tensions center around questions whose answer is a "shifting target," such as how much independence or, conversely, support to provide, these continuing tensions allow for continued re-evaluation of these central questions, as stake-holders struggle to resolve the tension they feel. Interviewees shared with researchers that they experienced these tensions frequently, and deeply, throughout their experiences with supported living.

### **"Because We Love Them" – Parents and the Tension Between Providing Care and Letting Go**

Parents and guardians of adults with Autism face multiple tensions and continuous transitions in their role in regards to their child. For some guardians they are conservators of their child's interest, maintaining legal decision-making authority even after their child reaches their age of majority due to issues of competency. Others serve as guardians and support their child in decisions that are their adult child's legal right to make. Still others step back to promote their child's independence. While the legal situation is black and white—conserved or not—for many parents, this is an emotional struggle with no clear answer. Letting go is not easy, nor always wanted. What level of support should remain in place? This issue is further complicated by tensions between guardians and supported living staff or caregivers. Parents need to feel that they can trust staff to take on the caregiving role that they had previously provided. Lastly, when the trust is in place between guardians and staff that allows for the ceding of the caretaking role, where does that leave parents' own lives and self-identity?

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The legal term for someone in the role of a parent to someone, regardless of their biological connection or lack thereof, is guardian. This word choice says a lot about our cultural conception of what it means to be a parent. A parent is a steward—a guardian—of their child and their charge. This identity of parent or guardian is a powerful one. It is a central life milestone. The guardians of adults with Autism have spent years, and even decades, of their life serving as the guardian to their child's interest. That is a lot of time to become entrenched in a role, and to have it come to define oneself. From PTAs to parent support groups, to Mommy meet ups and Mommy cards, parenthood or guardianship often becomes a central piece of a person's identity after it's achieved. When parents transfer the role of caretaker to professional staff--whether serving at a group home, other supported living environment, or in-home care—parents find themselves with a sudden void in their lives. The time, effort, and personal identity all rooted in caring for their child with Autism is shifted. Shaun, the father of an adult child with Autism living at Sunrise, Sierra, explained this process saying, "Now, we [my wife and I] are getting used to being together alone, without Sierra."

The process of letting go isn't easy, for parents or child. Shaun told interviewers that, "I missed her a lot more than I... expected." Shaun was surprised to find that he missed his daughter even more than he missed his neurotypical son when the latter moved away, which he suspected was because he had seen Sierra every day before she moved out, which wasn't necessarily as true with his son. Tonya, another parent of an adult child with an ASD living at Sunrise, expressed a similar statement, describing the

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loss of connection she experienced when her daughter moved away. At “some subconscious level,” Tonya described, when one’s child lives with them, a parent is always attuned to where their child is and what they are doing. That constant connection fades when a parent and child move to different domiciles. Instead of that subconscious knowing, a parent has to learn to trust another to hold that knowledge, and act upon it appropriately. It is not a transition parents take lightly, and the choice of whom to trust to assist is no easy one.

When an adult child moves from a family home to a supported living environment, a parent is ceding guardianship and stewardship to their child and the staff or care-givers in their new living environment. This is a difficult process for parents internally. Trust is essential. “We don’t want them living at home,” Lily, Sierra’s mother, explained, “not because we don’t love them, but –” She trailed off, and her husband, Shaun, finished for her, “...because we *do* love them.”

Trust between guardian and caregiver is necessary for parents to be able to feel comfortable with this change in role. Lily continued to explain that her “confidence in the staff... has really helped me step back.” When Lily talks about stepping back, she means stepping back from a more active caretaking and guardianship role. It was her confidence and trust in the supported living environment’s staff that allowed her to do that. Dedicated guardians do not ever stop being guardians, they simply allow someone else to take on all or some of that role, whether that’s their adult child, support staff, or a combination.



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When parents do not have trust, they feel distrust, which is a type of tension. Parents described feeling tension when they felt that they could not trust the staff or caregivers in their adult child's new living environment to strike the appropriate balance in various aspects of their role in their adult child's life, such as the right balance between allowing for their adult child's needed "alone time" while also pushing for the development of social skills and friendships, or the right balance between pushing for community participation while respecting personal choice--perhaps to remain engaged in more "solo" activities--or the right balance between promoting fitness while respecting personal choice.

Each of these areas of concern were in turn reflective of tensions. They are examples of a push and pull between different aspects and goals. Promoting independence and allowing for choice is a good thing, as is providing care and promoting personal growth. However, there is an inherent tension between them. It is not an easy balance to strike. Both are important and valued goals that are nevertheless often in opposition to each other.

Many residents at Sunrise have specific goals outlined in a document called an Individual Program Plan (IPP). Guardians, however, do not always feel that staff are striking that appropriate balance in regard to these goals—the trust is not there, which in turn creates inter-relationship tension, and role confusion for the parent. Tonya discussed with researchers how her daughter had three goals when she moved into Sunrise. Tonya felt these goals were simple and should have been easy to achieve: fresh air, good nutrition, and daily exercise. However, Tonya explained that she felt like she

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could not trust staff to ensure these goals were being met, or moved towards, unless she herself actively pushed for them. Tonya did not even feel confident that support staff were even aware of her daughter Kate's goals, let alone acting to assist Kate in the pursuit and attainment of them.

An aspect of the supported living environment that Tonya felt was actively contributing to this perceived lack of awareness and action towards Kate's progress was the high rate of staff turnover. When Sunrise changed the agency they used to hire their staff, and staff remained for longer periods, Tonya's confidence and comfort with staff and Sunrise increased.

Shaun and Lily also expressed an increase in their comfort and confidence in staff once there was a change in agency. An increased rate of staff retention, as well as better staff supervision and coordination was cited as crucial to this feeling of higher staff competence, and therefore higher parent trust and confidence in staff. Parents and guardians at Sunrise, as well as the Board at Sunrise, provide monetary bonuses and inducements to try and increase staff retention because of how much it helps to resolve parents' internal tension about who has taken on the caregiving role for their child. This was of particular concern for Shaun. Shaun told interviewers: "It's much better [at Sunrise, since the change in staff]. It's all about the staffing. It might be an award-winning architectural design, but if the staff isn't right..." He trailed off, shaking his head, non-verbally communicating with interviewers what little comfort or confidence he had in a supported living environment where parents and staff-members did not have the

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time together to establish trust, or were experiencing other impediment to the development of trust.

Typically, as a child ages, there is a fading out of responsibility. Over time, more and more responsibility shifts from the parent to the child. The legal system in the United States has established rules to keep decision-making power and responsibility with the parent in circumstances where it is decided by a court of law that this should be the case. This is often called conservatorship. In regards to those with an ASD in California, the relevant type of conservatorship is called a limited conservatorship. Limited conservatorships award an assigned, responsible, person rights of care for an adult with a developmental disability or an ASD. If the person with a developmental disability or ASD is already known to the Regional Center (a state agency which provides services to those with special needs), the process will go straight to a court hearing overseen by a judge. If the person with a developmental disorder or an ASD is new to the area, the local regional center will assess their eligibility or developmental status, first, before proceeding to the hearing. At the court hearing, the judge will specify what exact rights of care the responsible adult will have in regards to the person with a developmental disability or an ASD. This topic came up with some frequency at an observed meeting of the Board and a parent group at Sunrise. As parents spoke with researchers and each other, statements would often begin with phrases like “My child is not conserved, *but...*”

That “but,” that gray area, is another area of tension for parents. Tonya discussed with researchers that while her daughter was not conserved--and she would

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not want her to be so as to best develop her independence and self-care skills—she nevertheless had some mixed feelings on the subject of conservatorship. In other words, she was experiencing tension around this concept. Tonya shared how she wished there was a way she could cede day-to-day choices to Kate, while retaining control for (or at least the inviolable right to be consulted on) “major” decisions. Examples of the sort of decisions Tonya wanted to remain at least partially in her purview included medical decisions and decisions about where to live, such as whether to remain at Sunrise. Similarly, parents of conserved adult children discussed a tension between wanting to be there for their child, while also wanting to promote decision making skills, independence, and interpersonal confidence—partially because they were aware of the fact that they could not always be there for their child. Parents interviewed in this study seemed to prefer the idea of ceding at least smaller decision-making authority to staff, rather than other children they may have, siblings of their conserved child, discussing with interviewers how they wouldn’t want their “other,” neurotypical child to be forced into the role of advocate for their sibling.

This tension regarding decision-making power intersects with the potential for interpersonal tension between parent/guardian and staff/caretakers, and whether or not there is trust in that relationship. Following up on his wife Lily’s comments about her confidence in staff allowing her to “step back,” from her own role as care-taker, Shaun told interviewers that “...day-to-day decisions are happening without us.” This comment was made while smiling, during a conversation about the benefits of increased trust in staff, increased consistency in staff, and increased competency in staff, with the

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implication that this shift in who was making those everyday decisions was a good thing. That is not, however, to state that there is no tension. The tension over decision-making still is present for Lily and Shaun. When Shaun was asked what his goals were for his daughter, what he'd like for her going forward, Shaun's immediate answer was that he'd like her "...to be able to make choices and express her own desires—to us and caregivers." Shaun and Lily's daughter, Sierra, is conserved. Nevertheless, the pull of independence exists, and the tension between this desire of Sierra's family, and other, conflicting, desires, remains.

Shaun and Lily want Sierra to be able to "have more choice in her life." They also want to continue forward in the process of letting go, and ceding control to Sierra and the staff at Sunrise. However, they have goals for Sierra that they feel are important, but don't happen unless they push for them, such as Sierra socializing more, finding a friend, eating well, and exercising. They experience internal tension in trying to decide how much it is appropriate for them to push their daughter towards these goals, and they experience interpersonal tension between themselves and staff regarding a perceived lack of action on the part of staff. Shaun explained how he felt, telling interviewers:

I've talked till I'm blue in the face to try and get them [support staff] to work together to help her [Sierra] make a friend... Maybe if I lived closer to Sierra I could step in, but I don't think that's my job anymore—to make friends for her. That's part of why I moved her there [to Sunrise].

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Similarly, Tonya expressed that while she felt concern that Kate's goals weren't supported unless she advocated for them or reminded staff, she also felt "tired," and that she didn't want to always have to tackle that fight anymore. "I've modified my expectations [for Kate], because I'm old," Tonya said, "and I am accepting that she is doing *well*, just not well enough for *me*."

Tonya describes moving towards a resolution of another common internal conflict and tension for parents: their adult child's conception of what doing well means and their own. These conceptions are not always harmonious, and are frequently disparate. All four parents interviewed stressed that their adult child with ASD finding, developing, and maintaining friendships was important to them. Three out of four parents interviewed also emphasized the importance of frequent exercise, frequent time outside, and a diversity of activities in the broader community. When asked what she'd like to see for her daughter, Lily shared:

I'd like to see her expand her interests. As she got older, her interests have declined. She used to be more interested in farm animals and baking, but she doesn't want to do them anymore... And I'd like to see her integrate more with the community—make a friend at work and be involved in the church. [I'd like Sierra to] be more involved in activities outside of Sunrise's four walls. I'd like to see her happier.

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However, while those were Lily's goals for Sierra, she felt that the perspective of the staff was that "...you have to help the residents live the best life for them, not what other people want." That can create an internal tension for parents, who may have an emotional response to the idea of their child "missing out" on elements they feel are essential to a good life. Shaun followed up on his wife's comments, saying:

Everyone agrees, in principle, that Sierra should make her own choices, but [sometimes] they are antithetical to what we feel life is all about... she doesn't like to go outdoors, she doesn't like to meet new people, or do new things... so what she wants might be to sit in a dark room, meet no-one, and watch an endless loop of Disney videos, but is that right?

"I want her to do some of that," Shaun concluded, before trailing off, doubt and worry etched on his face as he considered the concept of a lifetime of children's films in a dark room, alone.

Tonya has her own concerns. She worries that her daughter, who has in her IPP goals to cook a meal at home three times a week, and to get daily fresh air and exercise, has gained ten pounds and is being taken by staff out to restaurants to eat too frequently. This is the kind of situation where interpersonal tension can begin to develop amongst stakeholders. If a resident doesn't want to exercise or leave her television to go outside for fresh air or a social opportunity, but their parent or caregiver wants them to do so, tension can arise between the triad. Internal tension can develop

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as well, as parents or caregivers wrestle with the question of when or how much to push. This internal debate can be seen in Shaun's tangled feelings regarding how Sierra can and should spend her time, and how the questions he had about it were ones for which he had no ready answers.

For parents, then, there are many sources of tensions surrounding their adult child with an ASD in a supported living environment. They have tension regarding the amount of space being a caretaker takes up in their own life, and what roles to take on when that changes. There's a tension, too, for parents in deciding when and how to let go, as well as the difficulty inherent in the transition itself. Letting go involves a ceding of control and responsibility, which can create not only tension within the parent as they try to decide how much caretaking to cede and to whom, but also interpersonal tension between the parent and the people who will be taking up or sharing those caretaking responsibilities: staff and their adult child. Trust and confidence in the interpersonal relationships can decrease the tension in letting go for parents, and distrust can increase it. The push and pull between providing a high standard of care and promoting a high standard of independence incites tension in parents as well, as they struggle with those two diametric goals, and what to do. It can also create interpersonal tensions between parents and caregivers, and parents and adult children, when there are differences in priorities and choices amongst these stakeholders, or members of the triangle.



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**“The Best Life for Them” - Caregivers and Staff Experience Tension Between Different Goals, Professionalism, and Friendship**

Hired caregivers or support staff can be present both in group homes, alternative supported living environments, and family homes as part of an in-home care program. Certifications, background checks, and the amount of training required can vary wildly between states and agencies. Regardless of the specifics of what is demanded, however, once hired these individuals are professional caregivers, who are spending a significant portion of their time with the individuals they serve. Supported living service-providers can be nurses, special educators, care providers, live-in support, personal care attendants, and even “paid roommates” (Ch. 6, CA WIC § 4689). For caregivers, perceived tensions can arise regarding: their own role as a professional and their role as a friend to the person to whom they provide services; how far to “push” residents in order to encourage growth, and the conflict between providing that encouragement and respecting residents’ own decisions, choices, and preferences; and their role when parent and adult child are experiencing tensions or conflict.

Training programs, guidelines, and literature regarding “caring” professions such as supported living service providers, can often emphasize the importance of maintaining appropriate boundaries between the service provider and client, though there is a growing awareness that overemphasizing boundaries can limit provider effectiveness and their positive relationship with their client (Hart, P. 2017). Tonya, Kate’s mother, felt that it was better for her daughter’s wellbeing that staff err on the side of friendship when it came to the balancing act between professionalism and

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friendship. Tonya had been concerned about her daughter's participation in activities outside of Sunrise. She was finding that the only outings staff were able to make appealing to Kate were shopping trips and Tonya wanted more for Kate. She wanted more diversity in her daughter's daily outings. Tonya explained to interviewers that Kate was only willing to go on outings for activities other than shopping when these outings were proposed by one particular caregiver, Brianna, who "treats Kate as a friend."

Lily and Shaun also commented upon the importance of the friendship caregivers can provide residents. Both parents very much want Sierra to be able to have more relationships and make more friends. However, Shaun's sense is that Sierra only "tolerates" her housemates (other adult residents with Autism who share a living space with Sierra), rather than being excited about their company in the same way she is when Shaun and Lily visit. "You don't get the sense that they are enjoying each other's company," he explains, though he does note that he feels that Sierra enjoys engaging in "parallel play" with them (co-existing in the same space but not necessarily engaging in the same or a shared activity). Lily feels that it is easier for Sierra and her housemates to forge friendly relationships with staff than each other. In that way, friendly relationships with staff may provide a more accessible social outlet for adult residents with ASD, while also increasing the effectiveness of caregivers, at least in terms of ability to make diverse daily activities take place with fuller participation.

That said, however, Tonya also stressed that one of the very most important things about Sunrise was how care-givers and staff *respected* residents. Caregivers felt an internal tension trying to balance these ideals. One such staffmember at Sunrise, Abbie,

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shared with interviewers that it is difficult to “practice what she preaches” in terms of maintaining strict professional boundaries, instead finding herself being respectful, yes, but also crossing into the personal sphere by being a confidante and friend to residents she has served. Caregivers, therefore, must face the tension between showing respect for residents through clear use of boundaries and strict professionalism, including a certain level of formality (University of Washington Oshkosh Center for Career Development, 2010), and the parent-reported increased effectiveness to their support when engaged in a friendly relationship with their client, and the benefit the friendship itself could have for a population that is frequently without friends (Friedman, Warfield, & Parish, as cited in Geurts & Schereen, 2015).

Another tension related to caregiver effectiveness is the tension between the caregiver’s role to push for growth and assist their client with ASD towards overall societal expectations (including parents’ expectations and legal expectations, such as the social integration discussed in the California Welfare and Institutions Code--which governs some of the law regarding supported living in that state--and the goals outlined in a resident’s IPP) and their responsibility to support and assist the client towards whatever it is that client says that *they* want to do, even if this means choices the caregiver (or parent) does not like or even increases isolation and regression of social skills. One staff-member, Patricia, shared her perspective, and how she preferred to err on the side of promoting and defending residents’ choice: “I think it’s easier,” she said, “when the service is focused on the person being served, as opposed to what we think is best.”

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Lily and Shaun chose Sunrise for Sierra because they prioritized her gaining independence. Even so, Lily has felt tension in her relationship with staff-members, who felt that their role was to defend the interests and choices of their client against the interests or preferences of others. These staff members prioritized defending their client's independence and right of choice over promoting assimilation or avoiding interpersonal tensions between themselves and residents' parents. Patricia, a staff-member evidencing that choice of prioritization, explained, "We believe we know what's best for people who are dependent on us, which I think can create some unhappiness... we need to really *listen* [to the individuals with ASD in residence]."

Other staffers, however, when faced with this tension, elected to resolve it by adjusting their behavior to better satisfy the wants of parents, though this may create interpersonal tension between themselves and the resident in their care, or other staff-members. Sam, a staff-member, explained that while there are parents Sam wishes were more or less involved in their adult child's life, "I just navigate that." "I'm becoming more Switzerland in this," Sam, joked, speaking of his self-established role as mediator between parents and care-givers as well, "How can I act and make the working relationship better?"

One care-giver, Brianna, was able to use her friendly relationship with her client to encourage her to be adventurous and go out on a greater diversity of outings. This reduced the internal tension her parents were feeling by assuaging their concerns, in turn reducing the interpersonal tension between them and their adult child's caregivers,

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all without increasing interpersonal tension between Brianna and Kate. Instead, it had a positive impact on Brianna and Kate's relationship, according to Kate's family.

The tensions caregivers face, just as the ones parents do, aren't always easy to resolve. They are internal and interpersonal. Caregivers are pulled towards professionalism and friendship both with residents or clients. That is an internal tension, and a question, caregivers must resolve. The best way to resolve it may be different for each caregiver-client dyad and may shift as their relationship grows and changes.

Brianna was the only member of staff at Sunrise who treated Kate "like a friend." She was also one of the longest serving service-providers working with Kate. Brianna had been with Kate the longest, and also had the closest relationship with Kate—quite probably not entirely a coincidence.

The interests and goals of parents and adult residents with ASD are not always aligned, which can exacerbate the tension caregivers face, as they navigate their relationships with both parties. That point of tension is further intensified by the legally binding goals of an IPP, which caregivers are obligated to pursue—a duty parents feel is often neglected.

Care-givers, on the other hand, can feel like their client's right to independence is being neglected. Lily described how the caregivers she had encountered took deep pride in emphasizing their role as stewards of their clients' "best life," including when that contrasted with her vision of what her adult child's best life should be.

Patricia is one such staff-member, and the concern was audible in her voice when she expressed internal tension she was feeling over how to best perform this role.

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Patricia shared her frustration that, as a neurotypical person, no-one tracks whether or not she decides to do something fun or how often, and no one chides her for choosing to instead relax at home if that is her choice. Why should it be any different for residents with ASD, she wondered. For her, policies such as tracking participation in activities feel like they err too heavily on the side of imposing others' ideas as to what is a good life upon the residents, rather than appropriately respecting their rights and independence as adults.

Even for caregivers such as Patricia, however, who feel certain that guarding their client's best life is their role, tension arises through the many different conceptions of what someone's best life may be. Does it involve diverse daily outings? What about social needs and integration? Fresh air and exercise? Parents report feeling that these are necessary to their adult child's best life, but also that their child often has a different opinion. Caregivers and support staff can look to conserved status as a guideline, as well as IPP data, but the black and white legal binary of conserved/not conserved does not always accurately reflect the complicated diversity of individual's needs and situations, as evidenced by parents' struggles over conservatorship, and hopes for a more middle path. Caregivers and staff, too, experience this intrapersonal and interpersonal tension about the best way forward for all stakeholders.

Another staff-member at Sunrise, Sam demonstrated this tension within the internal thinking process, as well as in relationships with other stakeholders, sharing with researchers:

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There is a difference between what parents think the residents should be doing, and what residents themselves want to do...but... with no structure, no encouragement, everyone would just be on their computer... So a little nudging is good... but I think that for me, that as I see those [participation in daily activities] numbers go up, sometimes I wonder if I need to be thinking more about choice...

The tensions care-givers experienced had many different roots. Another area of concern for some staff-members was balancing safety concerns against the right to privacy. In explaining her decision-making process regarding this, one staff-member, Patricia, shared how she attempted to use perspective taking as a way to resolve her intrapersonal tension: "I have to think to myself of what each stakeholder finds is most important... the world has their own trauma. They come to the table with their own trauma, and if we understand that [our jobs are easier]." Perspective-taking was again used to help Patricia when she faced tension regarding choosing what elements of residents' lives under her care to share with Sunrise administrative staff. "Would I want somebody to share that with my property manager?" she asked. "But, at the same time," Patricia continued, "the more [the administrator] knows, the more we all know, which affects the bottom line of health and safety..."

Another staff-member, Abbie, was yearning for collaboration and conversations as a way to help resolve the tensions she was feeling. Abbie was experiencing negative feelings and tensions over a specific policy at Sunrise: identity and address cards for

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residents, meant to assist in the case of a resident needing help to return home, who may not be in a mental space or have the skills in a particular moment to communicate where “home” is. Abbie worried that this potential emergency situation benefit was insufficient to warrant something that she felt was inappropriately labeling residents, and perhaps inviting ableism upon them. “It might be determined that it is worth the stigma, but I don’t think that conversation even happened,” Abbie worried. “Maybe internally,” she added, an unsatisfied note in her voice indicating that an external conversation as well would be welcomed.

A program in place to facilitate these sorts of conversations would allow others to understand Abbie’s concerns over the possible stigmatization invited by the identity and address cards, and allow those on the other side to explain their own fears and concerns that they feel these cards address. The conversation that never happened might be able to unlock a third path were it to occur, such as a card that has a physical address in case of emergency, but simply says “My Address:” or resembles a return address stamp, without naming the supported living environment Sunrise, which might be known in the community, and thereby accidentally disclose personal medical/diagnostic information without consent. Abbie’s comments demonstrate the desire for, and possible benefits of, avenues for stakeholders to explore and share their intrapersonal and interpersonal tensions.



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**“Blossomed” - Residents and Adult Children with Autism and the Perceived Tension  
Between Assimilation and the Unfettered Pursuit of Interests**

Residents with ASDs in supported living situations or environments face internal and interpersonal tensions in this triangle of relationships and stakeholders as well. It is important to note that those residents with ASD who expressed an interest in participating in this research were unfortunately unable to do so due to unexpected health concerns. This is a serious limitation. Findings regarding residents with ASD are therefore based on parent interview information and reports, caregiver interview information and reports, and on-site observations. That said, the detailed second-hand information provided by these invested stakeholders painted a striking picture of individuals feeling an internal tension between the enjoyment to be found in a more predictable, but isolated, world and life, and the enjoyment to be found in a more outward-looking, participatory, and integrated one. This includes questions about levels of social integration, pursuit and maintenance of friendly relationships, work, education, and activity opportunities. There was also an internal tension to be felt regarding their physical and metaphorical place in the world, with parents discussing how their adult child with Autism would both feel drawn to and excited about their out-of-home supported living environment, and returning to their family, or parents', home.

Residents have to face a balancing act between assimilation and integration on the one hand, and unhindered pursuit of their own interests and enjoyment on the other. This evaluation of interests and enjoyment is perhaps in turn affected by issues of social anxiety. Bundy et al (2015) found that individuals with ASD often experienced

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social anxiety at a level that affected their social participation, however there was still an emotional positive for the individuals on the Spectrum in participating in these social events. Lily spoke at length about how much Sierra enjoys her day program. Shaun stressed the social connections she has with workmates there, and how he felt that, with mediation and support from staff, those connections could bloom into friendships. However, both Lily and Tonya describe how their daughters aren't forming friendships with other residents, or in the broader community. These mothers emphasized how their child's places of work and worship were places where there was a great potential for friendships to form, but that their child needed additional support to make that potential materialize. "How could she not be lonely?" Tonya asked, of Kate. "I feel like she has more sensations of loneliness than ever before..."

However, Tonya also said that Kate is "more socially aware than she's ever been," and that "she interacts more, so she has blossomed," since coming to Sunrise. Co-existence without direct interaction, or parallel play, is something underlined by both Lily and Shaun as integral to their daughters' happiness at Sunrise. Shaun shared that Sierra "...likes to be around housemates and do activities with others around her." Tonya describes Kate as enjoying the feeling of "being around people without having to interact."

Tonya also, however, expressed concerns about social regression in Kate since she moved into a "segregated community." Shaun and Lily have noticed that the more time Sierra spends at Sunrise, in a community of peers with ASD, the more abstract and less representational her art becomes. While each image holds great meaning for Sierra,

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and Sierra could identify and explain what was in each picture, it is no longer accessible or comprehensible as a representational image to her parents, or, they believe, anyone else. To them, it feels like as Sierra spends more time with Sunrise and a community of peers with ASDs, her art becomes more and more her own, but also something she is less and less able to share with the broader world.

Shaun and Lily are both members on the Board at Sunrise, and shared with interviewers how surprised they were at the lack of participation in activity opportunities offered. Sunrise tries to create voluntary excursions, classes, and other events for residents, including events that are open-house in order to bring members of the local community into Sunrise for joint social opportunities. These have become harder and harder to arrange, due a lack of participation from Sunrise residents. It became more difficult for staff and the Board to arrange these opportunities after several instances where not a single resident showed up for an event. One aspect that is interesting to note is that while turn-out was low, sign-ups were much higher, perhaps indicating interest in an event thwarted by disorganization or subsequent social anxiety, but that without an explanatory voice from the resident community, that is purely supposition—literature-informed supposition, perhaps (Chen, Bundy, Cordier, Chien, & Einfeld, 2016), but supposition all the same. Turning participation into a competition, with a trophy awarded for the resident who has participated in the most events that month, has helped to increase turnout, though it is still a struggle for Sunrise and the Board.

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The parents interviewed for this study described the enjoyment they observed in their child during events and activities outside of their supported living environment, such as a skiing trip, family reunion or event, lunch out, or even manning a booth at the local farmer's market. However, despite the enjoyment observed once there, it has consistently been difficult for family and staff to organize and motivate residents to break with routine and get out in the broader world. That is one perceived internal tension observed by parents in their adult children with ASDs: an enjoyment and quality of life benefit to diverse daily activities, social opportunities, and other events, but some kind of block to the pursuit or acceptance of them, whether that is due to social anxiety, disorganization, a distaste for the disruption of routine, or something else we cannot know without the voice of those individuals.

Another perceived tension is over what *is* home for adult children with ASD. Shaun and Lily removed Sierra from Sunrise twice, because she seemed unhappy to them. Now, however, Sierra declines invitations for family trips she previously appeared to treasure, and the same occurs for "sleepovers" with Lily and Shaun. Sierra still enjoys visiting, but wants to return to Sunrise to sleep, rather than sleeping anywhere else. For Tonya the experience was almost inverted. Kate was the one who wanted to move to Sunrise—Tonya wasn't convinced that she should move out at all. Kate was very excited, however, and got Mom on board. She even chose her own future room from the blueprints of the yet-to-be-built site. However, now Tonya has concerns about how excited Kate seems to be to leave Sunrise. "That's not good, right?" Tonya asked,

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tension in her voice, as she described how happy Kate was on her visits away from Sunrise.

Shaun acknowledges how excited Sierra appears to be when she recognizes that they are close to Sunrise, after a visit away, but also notes that Sierra's shared living space at Sunrise is "functional," but not *friendly*. It does not seem to Shaun to have the sort of social connections of a home. Similarly, Tonya's single response to what her own goal would be for Kate was for all the residents in Kate's shared living space at Sunrise to eat together, to try and make it feel more like a home. Furthermore, Tonya notes that Kate doesn't invite anyone to her shared living space, nor does Tonya spend time visiting Kate there, as it doesn't feel sufficiently private. Shaun and Lily visit Sierra about twice a month, and wonder "is that too much? Not enough?" These parents have taken on a tension that they perceive to be existent in their adult children as to whether or not their supported living environment feels like their own home, or if it feels like a place they visit in between spending time in their family home.

### **"A Real Community" – the Environmental Role**

All of these interplays and personal feelings and relationships are taking place within the context of a specific setting. There are environmental factors at work that cannot be ignored. The internal architecture and structure of a housing environment affects individuals. Living environments that face each other, paths that physically bring people closer together, and shared spaces all contribute to social opportunities--at least of a parallel play like nature, if not necessarily shared activities. The placement of a home, group home, or other supported living site also affects individuals' options and

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choices, which in turn affect their internal and interpersonal tensions. A housing environment that is situated within a community, and, specifically, within easy walking distance to a community, allows for greater community involvement and integration. This paves the way for more social opportunities and daily activities. Staff-members who are also members of the local community have the knowledge base to take better advantage of these opportunities and better offer them to residents. Community nearness and connectedness also allows for greater intermeshing, fighting against the feelings of isolation or segregation that can develop.

Lily and Shaun have been involved in the design of Sunrise from the beginning. However, they feel that if they were to do it again, some of what was emphasized in the original construction of the site isn't as important as they had thought, such as the use of expensive sound-dampening materials. What they found did matter was situating the buildings so that they encouraged interaction through various elements. One such element was constructing the houses so that their entrances faced each other, so that people entering and leaving homes would see their neighbors. Another was paths that brought residents close to shared areas and each other's homes so as to encourage interaction, or at least shared space. Lily explains:

I think the way the buildings face each other, oriented around the community center, that open area, I think that's... been exceptionally good for our children.

There is a real community.

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Likewise, Shaun explains, “To me, that’s the whole point, [helping] people to whom socializing might not come naturally to socialize.”

Similarly, shared spaces such as the communal rooms in each house at Sunrise provide an environmental impetus to encourage social opportunities. “The combined living/kitchen space facilitates community time,” Lily explains, “cooking together, eating together, choosing a movie together...” Lily also notes that the swimming pool is another shared space that is used, but that residents will swim and then go straight back inside, not spend time together outside around the pool before or after swimming. ISP and IPP data support the use of the on-site hot-tub at Sunrise as another well-utilized shared space for residents.

Tonya feels that the benefit of communal space in each house could be strengthened by staff. She would like staff to initiate and support a shared meal-time for each house-- a sit-down dinner for all the residents in that particular home to help them strengthen bonds with each other. All parents interviewed expressed concerns that their adult child with an ASD was not receiving sufficient support and encouragement towards taking advantage of social opportunities and initiating and maintaining friendships. Shared spaces were an important first step for parents, but they wanted more. However, Shaun takes the time to stress that his sense is that it is also important that there are private spaces available. Every resident at Sunrise has their own bedroom, and Shaun has observed that all the residents in his daughter’s house, including his daughter, take advantage of that space for “downtime” alone.

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The physical layout of the environment can play a role in the tension parents feel about encouraging their child towards socialization and activities outside of their room and personal space and respecting their adult child's potential preference for greater privacy, familiarity, and routine. Shaun described this internal tension, worrying that Sierra isolates herself too much when given complete free reign over her own decisions, saying that he wanted her to do "some of that," as he knew it mattered for her, but that he feared it wasn't right or healthy for her to only "sit in a dark room, meet[ing] no one."

Social opportunities and community integration are prioritized by parents, and even California law, which expressly lists facilitating community participation as a supported living service. Tonya describes how she observes a tension in the local community in terms of how it views Sunrise, and Sunrise's place in terms of the broader, local community. Some in the community, Tonya feels, see Sunrise as elitist, because of the expense to build it and the wealth of many of the residents' families. However, having Sunrise so close to the local community allows for joint events, and Sunrise residents to be seen by some in the local community as members. "Kate," Tonya says, "is known in [town]." The local church has been welcoming, and provided social opportunities for Kate, including a church camp weekend. Lily also hopes that the local church community can provide social opportunities for her daughter, and wishes Sunrise helped to facilitate that more. Kate and Sierra both participated in local markets. Kate has created a business with support through an independent living charity. Sierra mans the booth for Sunrise's home-grown vegetables at the farmer's market. "When Sierra



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walks down the street,” Shaun shares, “there will always be a few people who say ‘hi.’”

Having the community within walking distance is something that parents felt contributed to community access, if not quite the level of integration they hoped. Shaun commented that the staff at the local market frequented by many residents don’t seem to be aware of Sunrise, or what it is.

Shaun and Lily spoke about how much they, as both Board members and parents of a resident, worked to try and bring community to Sunrise. They did this through open house events at Sunrise such as movie nights, a drumming circle, and tai chi, as well as bringing locals in either as volunteers or as paid temporary staff teaching classes to residents. Participation was often low, however, and the connections hoped for did not occur. Tonya shared her concern that Kate is now living in a “segregated community,” The farmer’s market and similar events continue to provide a chance for the shared space and interaction between Sunrise residents and members of the local community that parents value, if not to the extent they had hoped or planned.

Location within a community parents felt was essential to social opportunities and integration, as well as activity and work opportunities such as the farmer’s market. However, parents did feel that none of these were fully explored, and wanted more, a potential interpersonal tension with residents’ lack of interest in participating. There is also a potential for interpersonal tension with staff when parents’ disappointed expectations meet with staff’s difficulties organizing these opportunities. That difficulty for staff may arise either when staff are lacking the friendly relationship required to support adults with an ASD take the plunge to try something different, as seen with

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Brianna and Kate, or from residents' lack of interest in participating, as described by board members. Lily and Shaun, as both board members and parents, felt this last interpersonal tension keenly. Environment matters, as does the extent to which it is used.

### **Conclusion**

For the stakeholders involved in the complex issue of supported living environments for adults with an ASD, there are often many questions that arise. They are questions where the answers are difficult to find, and the answers may differ from person to person, and even change throughout someone's life. These questions and answers are often based in a tension, a push and pull between two conflicting ideals. Neither side is right or wrong, but it's difficult to know where on that spectrum between either side to land. Promoting independence and free choice is crucial, but so is assimilating into the broader community and providing support. Assimilating and integrating into the broader community provides important opportunities and access to indicators of a high quality of life, such as social, work, and daily activity possibilities. However, the ability and right of adults to listen to their own wants and needs and decide how they wish to spend their time, and have that respected, is also essential.

It is important for caregivers to have boundaries, and to be professional and respectful, but it is also important for residents to experience friendships. Furthermore, caregivers who have a friendly relationship with their client may see increased effectiveness, at least in promoting participation in a broader spectrum of daily activities. A good relationship between guardians and caregivers allows caregivers to

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feel reduced tension and turmoil about the difficult process of letting go. As a matter of respect and due diligence, however, caregivers need to “help the residents live the best life for them, not what other people want<sup>8</sup>.” Work programs and daily activities are “loved” by residents, and adult residents with an ASD are willing to go the extra mile for those with whom they share a friendly relationship, like many of us, and that friendly relationship enables those adults with ASD to more comfortably take risks involving more diverse activities and deviations from routine. On the other hand, personal choice, alone time to regroup, and privacy are important as well.

These tensions weighed heavily on the minds and hearts of participants in this study. They are tensions that are difficult to resolve. They are difficult questions, with a moving target of an answer. What answers there are, often exist in the middle. As Shaun said of the services his daughter Sierra was receiving, “-this is the right level of support. It’s not too much.” Not too much, but not too little. Stakeholders are often faced with a Goldilocks-like problem where many solutions may have to be tried, before the right one for that particular person is found.

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<sup>8</sup> Lily, describing the attitude of caregivers to whom she spoke.

## Chapter V: Implications

### Summary of Findings

The primary findings of this study include a strong emphasis by participants upon feelings and relationships. Participants expressed inter- and intra-personal tensions on a consistent basis. Stakeholders—residents with ASD, their families, and their caregivers—were all part of a “triangle” or a triad of individuals whose personal feelings and relationships with each other affected their experiences at the research site. Tensions often arose regarding conflicting, yet equally important, ideals, both of which mattered to stakeholders. Stakeholders then experienced an intrapersonal tension and struggle as they tried to resolve how to balance those contrasting ideals. Interpersonal tensions could arise when individuals did not resolve the tension between ideals in the same way and were in different places on that spectrum. For example, one particularly common (and intense) tension participants (both guardians and caregivers) felt was trying to find certainty and balance between promoting their adult child or client’s independence and respecting their choices as an individual and adult on the one hand, and promoting their own perception of what was a good life on the other hand, and wanting to help guide their adult child or client towards that ideal. Both of these are important goals, and ideals about which participants felt very strongly. However, there is conflict between them. Wanting to do both and not being sure on which side to err created tension within participants, and deciding to err on different sides (or different areas/shades of the spectrum) could create tension between participants, such as a parent feeling that they could not trust their adult child’s caregiver to sufficiently promote their growth and

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movement towards a good life, while the caregiver felt that they could not trust their client's parent to sufficiently value their client's independence and right of choice.

It is important to note that these tensions are not inherently negative. They arise from a place of caring, and out of highly valuing ideals. They arise because these individuals are stakeholders in this community and process, and care about what happens to their fellow stakeholders and their feelings. These emotions and tensions cause stakeholders to consider and reflect upon these difficult choices, and facilitate in movement towards compromise or third space that reflects the various ideals of importance in this process.

It can be implied that emotional supports, facilitated conversations, and other opportunities to develop relationships and trust as well as exploring feelings of tension are a needed support for stakeholders in the Autistic community and supported living environment. Feelings aren't physical, but they are central to our lives, and, therefore, supporting living environment stakeholders' healthy emotional tension and providing ways to explore and ease tensions is a "practical" support, even if it's not what one might picture as practical. Supported living environments should consider programs or opportunities for stakeholders to air and explore their feelings and intrapersonal and interpersonal tensions.

## **Implications for the Literature**

There were three key points of similarity between the feelings expressed by our participants, and the literature reviewed. All three related to issues of socialization. The first was the question of friendships, the second was the role of caregivers in terms of

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being a potential friend, and the last was the use of architecture to create and facilitate socialization.

The parent participants in this study, like others sharing their experiences and feelings with different researchers, strongly prioritized friendships for their adult children with ASD. It was an area of universal agreement amongst parents interviewed: they wanted their child to have more and deeper friendships, and they wanted that to be an area of increased support for their adult child with ASD. Additionally, parents felt that their children benefitted from social relationships with their caregivers or staffers that were more in line with friendships, and that staff-members with such a relationship were better able to assist their child's growth. One of the staff-members interviewed echoed this feeling that the development of a somewhat familiar and friendly relationship between caregiver and client was natural and of mutual benefit. This is in keeping with critiques of strict delineations in caregiver/client relationships, which argue that it goes against the grain of those individuals who are drawn into caring professions, and that it reduces trust, relationship value, and caregiver effectiveness, to be purely clinical (Hart, 2017). This is not to say that there should be no professional boundaries, as these are crucial to reducing instances of abuse, but that they need to be sensible and allow room for caring (University of Wisconsin Oshkosh Center for Career Development (CCDET) & Wisconsin Department of Health Services Division of Quality Assurance, 2010).

Lastly, the findings of this research echo the literature's emphasis upon the importance of social structures being a part of the design for supported living

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environments. Parents felt that the purposeful creation of shared spaces in the floor plan of Sunrise--both in the supported living environment overall, and within each shared residence—was essential. The existence of shared spaces within the residences allowed for more time spent in parallel play. Furthermore, it was held that having the houses facing each other encouraged residents to greet each other or have similar, short, social interactions. This is consistent with Gaudion, McGinley, & Kew's (2014) findings on the importance of building explicitly shared, social spaces into supported living environments for adults with ASD.

A unique finding of the research was the emphasis by participants upon relationships and internal feelings and tensions. Most particularly for parents and caregivers, there was a feeling of tension regarding finding the right balance between promoting growth and their own conception of a good life for their adult child or the adult they served coming into opposition with the equally important goal of respecting and emphasizing independence and a resident's right to make their own choices, even if those choices differed from those of the parents or caregivers. This finding contrasts with the importance of practical and physical (architectural) supports for many stakeholders described in research (Pellicano, Dinsmore, & Charman, 2014) and calls for more practical research directions (Krahn & Fenton, 2012).

Another area of difference was in terms of daily activities. Daily activities are described in the literature as crucial to quality of life and community integration (Tobin, Drager, & Richardson, 2014; Scheeren & Geurts, 2015). Yet, according to participants, daily activities, frequently called "enrichment," were not as appealing to residents as

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staff and board members anticipated. Members of the Board of Sunrise described the difficulty that they had in eliciting participation in daily activities from residents, to a degree where it was becoming more difficult to arrange for future daily activities as teachers and providers were disheartened by arriving one too many times to teach to an empty room. Caregivers described their frustration with the heavy emphasis placed upon daily activities, which seemed patronizing and potentially ableist.

### **Implications for practice and policy**

There are several implications of these findings for stakeholders and allies in the Autistic community. Firstly, the findings indicate that emotional support and facilitated conversations or other opportunities to air and explore internal and inter-relationship tensions are an important support for supported living environments to offer. Holding diametric goals (such as promoting growth and respecting the independence of adult children with ASD) creates an emotional tension within stakeholders, including both parents and caregivers, and can create tensions in the relationships between stakeholders if they have different opinions regarding where it is appropriate to be on that spectrum. These tensions force stakeholders to wrestle with difficult decisions, and questions to which there are no easy answers. Furthermore, the “appropriate” answer for many of these questions may change over time. Over time an adult child or resident may improve their communication and self-advocacy skills. This would mean that they became better equipped to express their own desires to others. In turn, such a development would suggest that perhaps a less conservatory approach is now needed. Alternatively, an adult child who experienced an unfortunate event recently, such as a



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medical situation, may need an increased level of support to help them navigate a suddenly more difficult and draining world. The tensions stakeholders are experiencing remind them of the different aspects to these complicated questions, and digging deep and truly wrestling with these internal and inter-relationship conflicts and tensions may allow all stakeholders to feel more resolved, and reach more informed and considered decisions that have weighed multiple sides and perspectives. Conversations about realistic daily activities and goals should be a part of these exploratory interactions, given the discrepancy found between caregiver descriptions and research expectations.

Secondly, a focus on facilitating friendships needs to be prioritized by supported living environments because of their importance across stakeholder groups and in the literature. Proactive measures are wanted, such as the physical construction of shared spaces, activities arranged in those shared spaces, social skills interventions and training, and facilitated social opportunities.

Thirdly, the role of caregivers as professionals and potential friends needs to be explored, and potentially re-examined in light of literary critiques (Hart, 2017) and parent and caregiver responses and feelings. Hart (2017) addresses the question of professionalism and connection between caregiver and client in caring professions, such as social work, nursing, and caregivers. The example of social workers working with at-risk youth was used to illustrate how a personal, positive, relationship increased the effectiveness of caregivers. This echoed the feelings of the participants in this study. Parents felt that those caregivers who had a more friendly relationship with their child were more effective in their caregiving, and caregivers described their struggle with

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keeping things purely professional, and how, in reality, a more personal relationship tended to form, due to the time spent together and the human connection between caregiver and resident. Parents valued these friendships, particularly in light of a perceived preference on the part of their adult children for the company and friendship of caregivers to others, including other residents.

All three of these elements are important for educators and educational policy to consider, as the educational system is responsible for individuals with special needs, such as developmental disorders and ASDs, until the age of 21. Many adults with ASD in supported living environments are below that age cut-off, and educational systems still have a duty of care. Furthermore, IDEA enshrines the goals of inclusion and the idea of a 'least restrictive environment,' and these issues are critical aspects to consider when constructing policy related to supported living environments.

The community as a whole has a social justice stake in this matter, as well. It is a matter of community interest to ensure the best access and quality of life for all members of a community, regardless of ability or neurological status or identity (neurotypical or neuroatypical). Ensuring community access and a good quality of life for all are civil rights concerns, and a truly supportive supporting living environment may be the best option to help some of our friends and community members achieve those goals.

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### **Limitations of this Research**

There are several limitations to this study that must be acknowledged. First of all, as a case study, findings may be limited to the research site addressed. Expanding these questions to more types of supported living environment would broaden findings' applicability and universality. The culture of the area in which the site is situated, as well as residents' families, may have an impact as well. Sunrise is located in California, and most of the residents at Sunrise are of a high socio-economic status and are white or European-American. High socio-economic status is associated with highly valuing thinness (Swami et al., 2010) which may be a factor in the emphasis placed by parents at Sunrise on physical fitness and weight-related goals in IPPs and ISPs. Secondly, due to personal health reasons, the two adult residents with ASD who were interested in being interviewed had to rescind their participation, without the possibility of rescheduling within the available time frame of this study. This means a crucial voice and perspective regarding this issue was lacking in this study. On-site observations and second-hand descriptions from family members and care-givers were used to try and give as much of a picture of this perspective as possible without direct input available. Lastly, as discussed in my positionality statement, I am an individual with friends who are less significantly affected by Autism, but without personal or family members who are affected by Autism, significantly or less so. I am therefore more familiar with a less significantly affected population, who strongly advocate for self-advocacy and the neurodiversity movement. My bias may therefore tilt towards prioritizing independence and choice over the achievement of "typical" life milestones or structures. I may not

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have the same understanding of the importance of balancing individual choice with promoting growth, due to, for example, vast differences in the level in which various individuals are affected by ASD.

### **Directions for Future Research**

The importance of intrapersonal and interpersonal tensions is an interesting and new direction for future research. It could prove fruitful to interview primary stakeholders (all three “points” of the triangle—residents, parents, and caregivers) before and after the implementation of a targeted program addressing these tensions. Such a program could consist of facilitated opportunities to air and explore their feelings and tensions with the goal of better communication and decision-making processes that honor the various perspectives and the multiple sides to many of these issues. In other words, it could prove beneficial to interview stakeholders before and after beginning a program to help them find a “third space,” or thoughtful compromise. Possible programs to implement include group social opportunities to develop trust and relationships, guided journaling, a Photo-Stories project, round table discussions, or group sharing facilitated by a trained communication professional or counselor.

Another important direction for future research would be assessing the applicability of these findings at other sites, including different types of supported living such as group homes or family homes, and different demographics, including those from different socio-economic brackets, and different ethnic backgrounds. A third direction for further research would be to see if these findings are applicable for adult residents, their families, and caregivers with differences other than ASDs, such as an intellectual or

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developmental disability without a comorbid ASD. Future research could pursue whether intrapersonal and interpersonal tensions are a cornerstone of the experience for families, residents, and caregivers regardless of the reason for the adult child or resident requiring ongoing support, and where that support is given, or if it is more specific to supported living for ASD or on-site supported living.

## Chapter VI: Conclusion

The number of people diagnosed with Autism or an Autism Spectrum Disorder (ASD) is rising (U.S. Dept. of Health & Human Services, Center for Disease Control, 2017). While many individuals on the Spectrum lead full, independent lives, some require support services into their adult lives. Supported living environments provide a place for individuals to be outside of their family home, but still receive support and assistance. The families and allies of those with ASD and the Autistic community have expressed concerns about a lack of housing—as of this writing the most recent conference of the local branch of the Autism Society had a theme of housing (SFASA, 2017). There is a housing crisis identified in the Intellectual and Developmental Disabilities (I/DD) community, and this problem of a lack of appropriate, available, housing is getting worse over time (The ARC, n.d.). Members of the Autistic community and their allies want real-world ideas and solutions that address what affects their daily lives, including such practical matters as housing (Pellicano, Dinsmore, & Charman, 2014; Krahn & Fenton, 2012). Some researchers have found that there is a lack of research that honors and listens to the voices of the community and its allies, and utilizes a person-centered or resilience based approach (McCrimmon & Montgomery, 2014). This research project has attempted to use a case example to amplify the voices of stakeholders in this issue, and learn from them about what issues affect their experience as stakeholders in the Autistic community and supported living environment, and what policies, practices, or other procedures supported living environments can implement to be as supportive as possible for adult residents with ASD and their families.

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### Primary Findings

In the interviews with the parents and caregivers of adult residents of supported living environments with ASD, parents and caregivers strongly emphasized their own emotions and relationships. Their interpersonal and intrapersonal (internal and inter-relational) tensions were significant in their experience of being stakeholders in supported living environments. These tensions were not necessarily negative, but mostly revolved around holding two opposing ideals that both had value but were contrary to each other. Of particular frequency and impact was the tension between wanting to promote their adult child or the resident's growth and ability to participate in and experience typical life milestones and conceptions of a good life, while simultaneously wanting to preserve their adult child or the resident's independence, and respect the adult child or resident's right of choice. Other, similar, tensions were expressed by the family members and caregivers of adult residents of supported living environments with ASD. Most of these tensions reflected difficult decisions stakeholders had to make, and a difficult balancing act to master. They often featured opposing, highly valued, ideals. For instance, Shaun and Lily struggled with the idea of how much to "push" their daughter, Sierra. Sierra, if left to her own devices entirely, they described, would choose to spend her day watching Disney films alone in the dark. This was far from the life Shaun and Lily wanted for Sierra. It was not, they felt, much of a life at all. They had an idea of what a good life for their daughter was, and it was not one half so sedentary or solitary as that. However, Lily and Shaun also wanted to foster Sierra's independence and respect her choices and wants. These ideas are

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contradictory. Both hold value, but they cannot simultaneously co-exist in their extremes. If we conceive of this push and pull, these different ideals, as existing on opposite sides of a spectrum, we witnessed how stakeholders struggled to resolve where on that spectrum it would be best to land—did they wish to err on the side of promoting growth, perhaps at the cost of some freedom and self-expression, or on the side of respecting their adult child’s independence and choice, perhaps at the expense of some long-term happiness or satisfaction?

Caregivers struggled similarly. They, too, experienced tension in regards to this question of balancing promoting both personal growth and independence for residents. They also felt tension in terms of balancing the opposing ideals of authentically caring for their client as a friend on the one hand, and maintaining a strict and appropriate professionalism and boundaries on the other.

Residents were perceived to experience a tension between enjoying the potential benefits of assimilation, on the one hand, and the ability to pursue their own selves and interests, unfettered and unjudged, on the other. Residents also struggled with what they perceived of as home. Lastly, residents experienced tension between the pursuit of activities that others in their circle viewed as of benefit to them, such as physically or socially active engagements, and personal reasons to not engage in such activities, such as other interests elsewhere, a preference for an established routine, or anxiety.

None of these tensions stakeholders experienced intrapersonally are easy to resolve. Furthermore, interpersonal tensions can arise as a result of them, such as when



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multiple stakeholders do not all agree on how to resolve these tensions. Invested individuals—stakeholders—may find themselves erring towards different ideals—existing on different places along those ideals spectrums. This can create tension between them. For example, a parent may perceive a caregiver as failing to appropriately promote growth, while a caregiver is similarly concerned that a parent is failing to appropriately respect choice, or vice versa. A parent may experience a lessening of tension and increased trust toward a caregiver whom they feel is demonstrating an appropriate amount of true care, who has become a friend of sorts to their adult child, while the caregiver experiences a spike in tension over concerns that they are therefore insufficiently maintaining a professional demeanor and respecting boundaries.

Many of the issues around which these tensions arise are issues where there is no clear or “easy” answer. They are questions that invite a struggle. They are, furthermore, questions to which the appropriate answer may change over time. An adult child may benefit from an approach that pushes for more growth at one point in their lives, but be better served by a lighter touch that allows them greater freedom of choice and independence as their self-expression and self-advocacy skills improve. Stakeholders advocating for a program erring more towards one side or the other may be witness to a side or facet of the adult child or resident that differs from the side another stakeholder knows. After all, every one of us is multi-faceted, and we may exhibit different behaviors and sides of ourselves in different contexts and situations. Jointly exploring these tensions, therefore, may help stakeholders be able to better

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consider multi-faceted problems from varying perspectives, and make better, and better informed, decisions of care, that more accurately reflect the complicated realities and situations they aim to address.

### **Additional Findings**

This case example research attempts to respond to gaps found in the existing literature, including by adopting a person-centered approach (McCrimmon & Montgomery, 2014), and focusing on real-world ideas for real-world problems (Pellicano, Dinsmore, & Charman, 2014). There were several key areas--in addition to the primary finding of the emotional impact and interpersonal and intrapersonal tensions--where stakeholders were able to share their experiences regarding supported living environments, and how they could best support residents and their families. First, parents of adult residents with ASD placed a high emphasis on the importance of social opportunities and development for their adult child. In short, in keeping with the literature, parents of adult children with ASD strongly valued their child having a friend, and the development of their child's social skills (Poon, Koh & Magiati, 2003; McMahon & Solomon, 2015). Social skills development, and social opportunity facilitation, were two areas parents felt their adult children could use more support in their supported living environment. All three parents interviewed shared a wish that caregivers proactively teach the social "rules" that would better allow their adult child to make and maintain a friend. Parents also wanted caregivers to assist in the creation of social opportunities to build these friendships, such as "play dates" for colleagues in a work placement program for adults with Intellectual and Developmental Disabilities (I/DD), or

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facilitated dinners with housemates at Sunrise and/or acquaintances from the community, especially local places of worship.

Hart (2017) found that those employed in caring professions experienced greater effectiveness in assisting those they served after forging personal relationships with them, using the example of social workers engaged with at-risk adolescents. An associated finding arising from this study was that parents prioritized friendship to an extent where they valued caregivers taking on that role in their adult child's life. While there was not the same preponderance of supporting information from caregivers, at least one described the importance and seeming natural inevitability of the development of friendly relationships between herself and her clients, and another staff-member expressed the wish that there was more of a tendency amongst caregivers to participate in activities *with* residents, rather than merely being present as support.

Lastly, parents and caregivers felt that the creation of shared space through building planning was important to help facilitate social opportunities. Shared spaces at Sunrise included each house's shared living room, kitchen, and dining space, which was a valued space for participating in parallel play according to parents, homes that face each other to encourage hellos and goodbyes, and pathways that converge together that wind throughout Sunrise. Individualized Service Plan (ISP) data at Sunrise supports the use of the gym and hot tub at Sunrise as another frequented shared space for residents.

The importance of shared spaces is in keeping with Gaudion, McGinley, & Kew's (2014) research regarding the construction and design of supported living environments

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for adults with ASD. Differing from this established research, however, parents interviewed did not feel that sensory dampening materials and measure were of great use to their adult children in residence.

### **Conclusion**

In order for supporting living environments for adults with ASD to most effectively support stakeholders, they need to honor the feelings and tensions of stakeholders, and work to facilitate the exploration and sharing of those tensions and feelings. Mediated sharing or talking opportunities can help build trust and the chance to better learn where on the spectrum of these difficult decisions various stakeholders exist. Photo-stories or similar methods for feelings-sharing and perspective taking could further this process of the building of trust between various stakeholders in the “triangle” (residents, their families, and caregivers/staff). These social opportunities would also help parents realize they were not alone in their feelings, and help parents and caregivers realize that many of the tensions they experience are shared and, in fact, similar to one another’s. “We’ll each have our own view of what it [the best choice, or path forward] is,” Abbie said of caregivers and their ideas. “And if you talked to the families [of residents] it would be the same. That’s what I want for Sunrise,” she continued, continuing to explain how she wanted all different stakeholders to be able to come together and mutually benefit from each other’s ideas.

In short, supported living environments are like any other home: in order to truly become one, they must have time together as a community and opportunities to be open and honest with each other about their feelings, emotions, and wants. From this

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place of togetherness and strength, different perspectives can be heard, and important, difficult, decisions can be made, as informed by the multiple voices of the supported living environment, their experiences, their hopes, their fears, and their strengths.

Ultimately, the most practical, real-world, support supported living environments must offer is the time and investment in each other, and respect for each other's feelings and perspectives, to be more than a house, but a true community: a home.

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What Makes a House a Home?

**Appendix A: Questions for Parents/Guardians**

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### Appendix A: Questions for Parents/Guardians

1. What are you most proud of your child accomplishing?
2. Tell me a little bit about how you came to choose here for your child?
3. What made this residence feel right for your child?
4. What does your child like to do at Sunrise?
5. Who are your child's friends?
6. What do they do together?
  - a. How often do they meet?
  - b. How *did* they meet?
7. What do you think is most important about this residence?
8. Do you feel like your child has made progress here?
9. What supports does your child need?
  - a. Do you feel that they are receiving them?
  - b. What do you feel could be done to better support your child?
10. What would make you change residences?
11. Is there anything that worries or concerns you?
12. Is there anything you wish was different about this residence?

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**Appendix B: Questions for Caregivers & Staff**

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**Questions for Caregivers & Staff**

1. How did you get into this field, and what is your experience?
2. What do you feel is your role at Sunrise?
3. How do you feel about working at Sunrise?
4. What are the times that fulfilling your role has been easier or more difficult, and what made it so?
5. How would you compare Sunrise services to other, similar, clients?
6. What do you think is most important about Sunrise?
7. What helps you do your job?
8. If you could change something about your job or role at Sunrise, what would you change?
9. If you could change something about Sunrise, what would you change?
10. What impediments do you feel there are to you providing the support you wish to, at Sunrise or other settings?
11. How would you describe your relationship with the parents of residents?
12. How would you describe your relationship with residents?

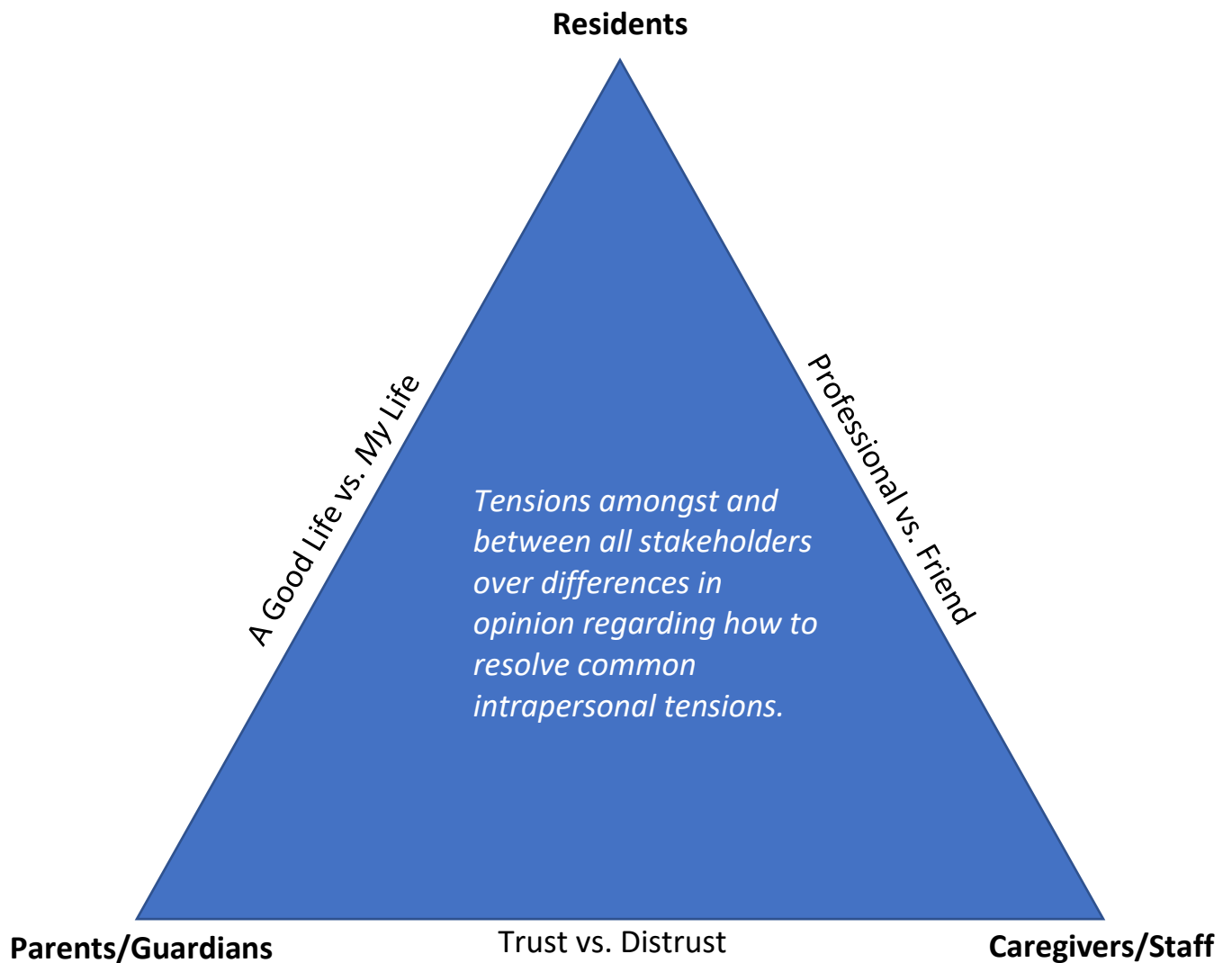


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**Appendix C: Figure 1. Interpersonal Tensions Triangle**

# What Makes a House a Home?

## Appendix C



*Figure 1.* Interpersonal Tensions Triangle.

A representational image illustrating interpersonal tensions amongst primary stakeholders in supported living environments.

What Makes a House a Home?

**Appendix D: IRB Approval Letter**

What Makes a House a Home?

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July 12, 2017

Jacqueline Urbani  
50 Acacia Ave.  
San Rafael, CA 94901

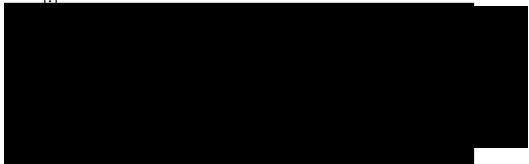
Dear Jaci:

I have reviewed your proposal entitled *Adult Independent Living Outcomes for Persons with Autism Spectrum Disorders* submitted to the Dominican University Institutional Review Board for the Protection of Human Participants (IRBPHP Application, #10565). I am approving it as having met the requirements for minimizing risk and protecting the rights of the participants in your research.

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,



Randall Hall, Ph.D.  
Chair, IRBPHP