

## Cultivating Empathy and Community for Adults with Disabilities: Germany's "Die Lebensgemeinschaft e. V." of Sassen and Richthof

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### **ABSTRACT**

Sassen, a German rural community, cares for mentally disabled adults with the purpose of providing them with the empathy, freedom, and community that other institutions often fail to provide. Through participant-observation and interviews, this study examines the ways in which this isolated community does not deny disabled individuals of their humanity. Sassen has full-time, live-in caretakers that care for their own surrogate family of disabled residents, creating an empathetic, and personal community. Through its isolation from society and its live-in staff, Sassen goes beyond ensuring their residents' survival and provides them with the freedom and empathy to engage in romantic relationships, belong to a family, and have a sense of purpose through their jobs that help sustain their community – to live and not just survive.

**Keywords:** disability, kinship, community care, Sassen

provide them with as typical of a life as possible by living, working, and playing with them. To them, this treatment preserves their dignity as humans (Eckman 2016) in that the boarders lead social lives, develop genuine personal relationships with others, and develop a sense of purpose – all of which remains not easily achievable in institutionalized, shift-based care. Previous studies on older, similar communities have demonstrated the effectiveness of family-based care for the disabled. Based on findings by Henry R. Stedman (1890) who inspected a community that used family-based care rather than institutionalized care, placing mentally disabled adults in a more domestic and natural environment increases their well-being far more effectively than institutionalized care (Tuntiya 2006, 323). Additionally, in a case study of Geel, Goldstein, Godemont, and Crabb (2000) suggest that the community's integration of the mentally disabled helps break down the dehumanizing stigma against mentally ill patients by acknowledging and appeasing their human needs rather than limiting the scope of their care to food, shelter, and hygiene.

As dictated in the Social Model of Disability, most Western societies tend to deny their impaired members agency in their own lives in order to protect them from a society that is not designed for them. Such denied liberties include the right to engage in romantic and sexual relationships, to pursue work and careers, and to move freely beyond the confines of their living space – in essence what makes us *human*. This institutionalized denial of such liberties and fundamental human experiences is what disables them, not their mental or physical impairments (Morris 2001, 1-3). Therefore, due to Sassen's incorporation of the Social Model into their model of care, I refer to the villagers as disabled in the context of disabling institutions, practices, and social statuses, and hegemonic stigmas against people with mental impairments. I use the term 'impaired' only in reference to the physical or cognitive abilities and needs of specific villagers. The village of Sassen thus reevaluates notions of humanity by establishing a safe communal living space, separate from society, that *enables* the mentally impaired to exercise the free will, agency, and rights to a greater social purpose and belonging that, at the time of its founding

The question of care for the mentally disabled highlights the broader values and principles of a society and culture. In considering care for their mentally disabled members, societies address questions regarding what rights and liberties they should or should not be afforded and how they will fit into a world that requires individuals to possess certain cognitive abilities and independence. For four weeks in the summer of 2016, I lived, worked, and conducted fieldwork in a unique community for mentally disabled adults (called villagers) in rural Hessen, Germany called Sassen.

Sassen's fundamental philosophy is based on the perception that mentally disabled adults not only need, but also yearn for the lifestyle of any other adult. I studied how this community provides its villagers with makeshift families that emulate the support and empathy of an effective and loving family unit. The community expands notions of kinship beyond the tradition of the nuclear family by creating familial ties between previously unrelated individuals. Caregiving in Sassen is therefore not incentivized by financial reward, but more by feelings of duty and empathy to family members who require care (Allen and Ciambrone 2003, 208). By blending work and home life together, having live-in employees establishes a much more personal atmosphere, rather than the professional ambiance that shift-based care engenders.

Sassen is by no means the first community to use a model of family-based care for the mentally disabled. In the small Belgian town of Geel, families have been taking mentally ill individuals (called boarders) into their homes and caring for them. Instead of trying to heal or cure their mental disorders as institutionalized care does, the people of Geel simply try to

in 1968, normative German society and the rest of the world denied them (Müller 2008, 7). It all began when “die Lebensgemeinschaft e. V.,” the organization that established Sassen, was set up.

## History of “Die Lebensgemeinschaft e. V.”

Influenced by Rudolf Steiner’s philosophy, in the 1960s, a group of German intellectuals – Dr. Wilhelm zur Linden, Hanno Heckmann, and Ruth Lossen – began to hold regular meetings to discuss alternative ways of living, along lines suggested by Steiner’s philosophy. One day, Dr. zur Linden invited his colleague, Dr. Karl König, to one of these meetings. In the 1940s, König had founded a small village community in Scotland for children with mental disabilities after he fled from Nazi Germany (Ahrens 2008, 9). This community was based on Steiner’s philosophical principle that every human possesses a healthy soul regardless of any illnesses or developmental impairments that may or may not be present (Hart and Monteux 2004, 68). The goal of König’s community was to nurture the soul of disabled children through education and community. After König’s presentation about this community, Hanno Heckmann was inspired to dedicate his life to working with the disabled community.

Along with his colleagues, Heckmann in 1965 founded the organization “Die Lebensgemeinschaft e.V.” in 1965. In an effort to gain more experience in caregiving for adults with mental disabilities, Heckmann worked in Lehenhof, another community that König founded based on the same principles as the one in Scotland; it was the first of its kind in Germany. Eventually, Heckmann worked in a community for mentally disabled children in Bingenheim, Germany. At this community, there was a group of eighteen year-olds who were no longer allowed to receive care in the community because they were no longer minors. They had to either return to their parents or go into a psychiatric ward. Realizing that there was no place in Germany that cared for *adults* with disabilities in the same way as König’s community had, Heckmann decided to found his own. In early January of 1968, Heckmann met Kurt and Doris Eisenmeier,

intellectuals who were eager to apply the ideologies of Rudolf Steiner to the needs of disabled adults. After exchanging ideas one evening, they agreed to work together to found communities for mentally disabled adults whom they would call villagers. These villagers would be put together into makeshift families run by abled house parents who would live in houses with them. Over the course of that year, Heckmann and the Eisenmeiers had founded the village of Sassen in the countryside of Hessen with the help and dedication of their friends, volunteers, and private donations. Hanno Heckmann became the house father of Sassen’s first family (Yong 2014). Although his family only had only sixteen villagers, Sassen eventually grew to have fifteen families, and a few miles away another village called Richthof was founded in 1977. Today there are 250 villagers living in Sassen and Richthof – 130 in Sassen and 120 in Richthof – and 150 employees.

For the summers of 2014, 2015, and 2016, I worked in Sassen as an intern. In 2016, I conducted fieldwork alongside my duties as an intern. My responsibilities included tending to the various needs of villagers, working in the garden and household, and facilitating free time with the villagers. One of my most important tasks, however, was adapting to lifestyle and mindset of this unique community.

## Modern Day Sassen

### Daily Life and Routine

Like any other community, Sassen has daily routines and a specific lifestyle that keeps it running smoothly and reflects a community-focused mentality. Sassen was founded to cultivate a lifestyle that reflects Rudolf Steiner’s anthroposophical vision: a way of life that perpetuates an image of humanity that reflects a more caring, selfless, social, and freer side of human nature. Sassen was founded in order to create a safe environment for mentally disabled adults of all levels of ability to live as freely and autonomously as possible without the expectations, dangers, and requirements of modern society.

One long paved road leads into Sassen from the nearest town, Schlitz. When I returned to Sassen in the summer of 2016 and drove along

that road leading to the village, I saw wide landscapes with cows until I eventually arrived. It all looked the same as always: the quaint, large houses scattered across a vast property connected by paved paths; the little shop in the center that sells toiletries, food, coffee, souvenirs, and various household objects handcrafted by villagers in the woodshop, ceramics studio, and weaving studio. On the southern side of the village, the farm housed the cows and chickens that were tended to for milk and eggs, while on the north side, the garden workers harvested various fruits and vegetables for the entire community. In the center of the village was a large pond that villagers sometimes swam in. Sassen is surrounded by farmland and forests that are popular places for strolls.

There are fifteen family houses in Sassen, and around seven to twelve villagers live in each house along with their respective house parents. House parents are fulltime employees who live in the family houses with the villagers and raise their own children (if they have any) there as well. Usually a married couple or a single parent, they are provided with their own section of the house for office space, and bedrooms for themselves and their children to which no one else has access. For all intents and purposes, this house and Sassen is their home, engendering a surrogate family for the villagers, as well as for the house parents and their children themselves. Each family eats breakfast, lunch, and dinner together, goes on field trips, and essentially does what any other family would. Some families have fulltime employees who commute into work each day to help around the house with cleaning, cooking, and caring for the villagers who need help showering, brushing their teeth, shaving, and putting on their clothes. However, most families rely on interns for those types of caretaking responsibilities. Interns are typically young adults and teenagers who stay with a family for either a few weeks for a high school internship or for up to a full year.

On a weekday morning, breakfast is served at 7:30AM in all houses. Everyone wakes up however early they need to in order to be ready for breakfast. Interns wake up around 6AM in order to help some of the villagers get ready, as

well as help set the table and prepare breakfast. Villagers who can get ready independently have their own specific duties, such as loading the laundry, emptying the dishwasher, cutting the loaves of bread, and setting the table. After breakfast, everybody goes to work at 9AM. There are several types of work in the community, such as household work, ceramics, woodwork, weaving, baking, gardening, and farming. At 12PM, the villagers return to their respective houses for lunch and then take a midday break until they go back to work from 2PM to 5PM. After dinner at 6PM, the villagers can choose to relax, take a walk, play games, or attend an event that the village plans each evening, such as concerts, dances, drawing classes, and other activities. On the weekends, villagers do not go to work, but help around the house with the family – tending to the garden, cleaning the house, or going on a walk. It is also common to go on a day trip to go to a nearby town, eat at a restaurant with the family, and walk around the shops. In the evenings, families like to play games, watch a slide show of one of their recent trips, or a watch a movie. While everyone is actually free to do what they like, villagers, interns, and house parents alike tend to spend time with each other and participate in most group activities.

There are two organized times for vacation per year: two and a half weeks in the winter over the holidays and five weeks in the summer. These vacations give villagers the opportunity to visit their families back at home, take time off from the workshops, or go on a trip. Villagers have three options during the vacations. They can either visit their parents, siblings, or guardians, go on field trips to other places in Germany or neighboring countries (organized through “die Lebensgemeinschaft”), or stay in Sassen or Richthof mixed into various vacation groups. What each villager does during vacation time largely depends on his or her family situation and physical and cognitive ability. Some villagers do not have families that will take care of them during the vacations. Sometimes their parents are too old or have passed away, and sometimes not all villagers are in contact with their home families. In such cases, Sassen organizes many vacation groups that go away to places like the Black Forest, the

Bodensee, the Netherlands, or even Italy, and also groups that stay onsite in the community.

These vacation groups consist of villagers from various families from both Sassen and Richthof and are led by coworkers. House parents tend to take this time as their own vacation. The able-bodied villagers often go into the vacation groups that leave the community. This allows them to have experiences outside of the village too. Those unable to participate are put into onsite vacation groups; however, some able-bodied villagers stay in Sassen or Richthof out of choice too. These groups undertake day trips to nearby places, like the zoo or aquarium, the theatre, and other events. Two circus performers run a clinic in Sassen every summer, teaching villagers clown tricks and dancing. Many musicians also come during the summer to perform for the vacation groups.

For the first two weeks of my stay in the summer of 2016, I stayed with Julie's family for the third time. Julie is a single house mother whose oldest children have already left the house, but she has one daughter – Sandra, a high school senior – still living in Sassen. Ten villagers live in this house. In the summer of 2014, I had only spent three days in the house getting acquainted with the type of work for which I would be responsible before the villagers all went on vacation and were scattered into various vacation groups. In the summer of 2016, however, I spent three weeks living there, working in the household, and caring for two villagers, Erik and Lars. In the mornings, I would wake up around six o'clock to shower myself, and then wake up Erik, shave his face, wash him in the shower, pick out his clothes for the day and help him get dressed. Afterwards, I would proceed to do the same with Lars.

### Humanity, Freedom, and Security

The villagers of Julie's family cover a wide spectrum of physical and cognitive abilities and therefore have varying degrees of responsibility and freedom. When I first met Jonathan in 2014, he was standing right outside of the house, quite relaxed and minding his own business, smoking a cigarette. Julie told him to go show me around Sassen's beautiful property, and he proceeded to introduce himself and welcome me to the community. His

demeanor and the fact that he was smoking led me to assume that he was coworker, not a villager; I did not think that villagers would be permitted to smoke. As we walked through the village toward the pound, I was met with a surprise. A woman with a speech impairment, whom I correctly identified as a villager, approached Jonathan and kissed him on the lips. Not only was I wrong about Jonathan being a coworker, but I now found out that villagers were not only allowed to smoke but also be in romantic relationships. The woman's name was Katja, and she was Jonathan's girlfriend.

It had embarrassingly never occurred to me before that moment that the villagers would possess the same emotional and sexual needs and desires as everyone else; it was quite naïve of me to think otherwise. Most people have lived their lives largely amongst abled members of society and do not have an in-depth understanding of the disabled community, engendering a disconnect between abled and disabled individuals. At lunch one day, an intern, Sophie, even recalled her boyfriend's extreme awkwardness, discomfort, and shyness when visiting Sassen. Both my naïveté and her boyfriend's discomfort reflect the lack of interaction between the disabled and abled in society and the lack of education about social perspectives of disabilities. With little interaction between these two spheres, the abled frequently fail to recognize the humanity in disabled individuals whose behaviors fall outside the predetermined societal norm. By essentially reducing the disabled to their impairment rather than placing their personhood at the forefront of their identity, the abled perpetuate an attitude that sets the disabled apart as outcasts and discredits them as dependent and incapable beings (Tregaskis 2004, 7).

As a result of this perception, the abled tend to cast them into devalued social roles, deem them as burdens of society, or neglect their needs as human-beings. This stigmatization marginalizes and dehumanizes them by leading to their loss of autonomy, freedom, and access to essential human experiences in institutional settings. This attitude is cyclically reinforced in that the abled typically are not exposed to institutional and public spaces which encourage

or enable the mentally disabled to enjoy such freedoms (Race *et al.* 2005, 509-511). Therefore, when we think about the type of care that should be given to disabled individuals, we think about what needs must be fulfilled in order for them to merely survive – food, shelter, and hygiene – and once those needs are fulfilled, our minds rest at ease. We do not, however, think about what needs must be fulfilled in order for them to be human – to *live*, rather than just survive.

That is when I began to see more of what Sassen provides for the villagers. Sassen reevaluates notions of humanity to *include* the disabled community. It integrates both the theory of Social Role Valorization (SRV) and the Social Model of Disability into its social structure and philosophy. As in the Social Model approach, Sassen puts the villagers' personhood rather than their mental and physical capabilities at the center of care (Hughes 2011, 508). Sassen acknowledges their needs as human beings to have genuine relationships and agency in their own lives, thus combating the damaging stigmatization they tend to face. Along the lines of SRV, the community gives its villagers meaningful social roles regardless of physical and mental capabilities. Rather than being discredited as incapable, each villager is assigned routine responsibilities which help sustain the community (Gibson 2006, 190; Wolfsenberger 2011, 436). Sassen refuses to give in to the dehumanizing stigmatization that leads the abled to neglect the human needs and value of disabled individuals. Thus, by providing the villagers with a safe space to exercise freedom and agency, this community humanizes them in a way outside society does not. Living here has forced me to ask myself, "Why shouldn't they be allowed to have romantic relationships? Why shouldn't they be allowed to smoke a cigarette or have a beer?"

Sassen, however, does not just let the villagers do whatever they please. While the community acknowledges their human needs and desires (as in the Social Model approach), it must and also does acknowledge the role that cognitive ability plays in decision making and one's personal physical health (as in the Medical Model approach), striking a balance between

the two (Hughes 2011, 509). The impairments of some villagers increase the risks of alcohol or cigarettes, so that must be taken into consideration, as well as parental consent. In the case of smoking, typically the villagers arrive in Sassen already possessing the habit; hardly ever do non-smoking villagers ever express interest in smoking. Regarding relationships, parental consent from both parties are required in order to ensure that each person in the relationship is comfortable, safe, and consenting. Nonetheless, despite the acknowledgment of the risks of providing the villagers with too much agency, security does not take saliency over freedom in the community.

Certainly, there are risks of letting villagers go on walks alone, smoke, drink, or engage in romantic and physical relationships. It would of course be safest to keep all of the villagers under constant supervision. Instead, house parents believe that the villagers should have as much freedom as possible within their individual needs. For example, a villager named Ulrich used to be very independent. He was allowed to take walks on his own around the village, and his house parents did not worry about him. However, once he started developing Alzheimer's, he began leaving the village at random moments throughout the day. His degeneration was gradual, so his house parents had to feel out how much freedom they could trust him with. His house parents cautiously monitored him and eventually stopped letting him take walks without supervision. Evidently, Sassen acknowledges both the role of individual cognitive ability in decision making and the need to have agency and human desires fulfilled in one's life by creating a safe space, separate from the outside world, where such freedom can be explored.

### Lifestyle vs. Work

Although the mentality behind Sassen provides such amazing personal care and community for its villagers, I initially could not help but think about the sacrifices the house parents have to make in order to make this possible. Julie is on the job 24 hours a day, seven days a week until she retires. The first time I came to Sassen, I had a very difficult time adapting to the new environment because I knew I would be on the

clock throughout my stay in the community. I could not go home after my shift was over because there were no shifts – nor did I ever have a day off in my five weeks working there. Unlike me, however, Julie does not get to go home and relax after five weeks of work; her work technically never ends.

Once I began working for Mark in 2014, he made me realize the mistake in my mentality about this type of work. He sat me down and told me not to think of my role as a job, but as a lifestyle. He warned me that if I perceived it as a job, it would be the longest, most painful five weeks of my life; essentially a never-ending shift. If I perceived this as a lifestyle, however, then the weeks would fly by. Objectively, the job was not difficult work. I had to shower, clean, and change the villagers' clothing, which only takes half an hour. The rest of the day, I would go on walks with them, go to events with them, and most importantly, bond with them. There was a lot of drinking coffee or tea and eating cake involved in this job. However, I always had to be present if something went wrong with one of the villagers. If I constantly waited for free time to do whatever I pleased, the job would become unbearable because that free time would never come. Essentially this community was a place in which people live together in nice houses on a beautiful farmland property, help those who need it, and work together in workshops in order to help out the community and provide the villagers with a sense of purpose. By understanding this mentality, I could finally enjoy living in Sassen.

Mark, in a conversation we had had after dinner once, emphasized the name of Sassen's organization: "Die Lebensgemeinschaft e.V.", which translated means, "the Living Community". In order to prevent abuse in the workplace (such as overworking employees and mistreating villagers), over time the German government has demanded workers from homes like Sassen to keep detailed records of everything that happens each day for each villager. Sassen, however, barely keeps such records, arguing to the government that they are not a working community, but a living community, as the name suggests. House parents cannot perform their job very well and cultivate a loving, empathetic environment if

they are cooped up in their offices, documenting every hour of every day.

Furthermore, the community in its very nature blends work and home life in a way that makes it difficult to distinguish the two. Going to the garden and working from 9AM to 12PM, for example, may be considered work; however, emptying the dishwasher for the entire family could either be construed as work or merely a household chore to keep the house tidy. Everyone has their own responsibilities in the household that could be interpreted as work or as simply helping out the family or the community. House Mother Julie argued that it would be ridiculous if she had to record how many minutes it takes Erik to load the dishwasher, Thomas to dry the dishes, or Leah to prepare sandwiches for dinner. In the outside world, going grocery shopping, cooking, cleaning, and cultivating a loving environment for the family is not considered work, but ways in which families function outside of the workplace. In Sassen, however, a house parent's home is their workplace and vice versa. Employees do not perceive work and home life as two distinct entities. Unlike shift-based work, being a part of Sassen is a way of life that builds the bridge between work and home life, engendering a lifestyle that liberates one from working in order to enjoy eventual free time, or as a means to an end. It allows one to live as an end in itself and remove the stresses of an undesirable work life.

Retired house mother Caroline had worked for "Die Lebensgemeinschaft e.V." for almost forty years, and she contrasted her time in Sassen with a shift-based home she had worked in previously. At her old job in northern Germany, the care recipients also worked, but not onsite. Caroline and her coworkers dropped them off at various industrial work sites in the morning and picked them up in afternoon. On weekends, instead of coming back to the community, the residents were picked by their respective parents, brought home, dropped off at work on Monday morning again, and then picked up by Caroline and her coworkers. Essentially, the employees at this home would only see the people they were meant to take care of in the afternoons, evenings, and quickly in the mornings from Monday to Thursday each

week. Furthermore, the shift-based work meant that each respective employee saw them even less than that.

While telling me this over a cup of coffee one afternoon, Caroline complained about the individualistic atmosphere and mentality, as well as the lack of empathy, that comes as a result of shift-based care. The atmosphere at her old job was very professional and impersonal. Coworkers did not necessarily try to befriend one another, nor did they make a strong, sincere effort to engage with the residents they were caring for. In every common area, there were televisions to keep them busy, unlike in Sassen where common technologies such as televisions and internet were quite limited and restricted. According to Caroline, the moment work becomes shift-based, the employees' mentality becomes one that separates work and personal life distinctly, thereby altering the nature of the relationships between coworkers and residents. When care recipients switch caretakers every few hours, the relationship remains an impersonal, professional one in which trust on the side of resident and empathy on the side of employee does not form in the same way that it does between house parents and villagers in Sassen. Based on Caroline's experience, the sentiment of the care that shift-based work provides seems to be one of necessity and work as a means to an end rather than empathy and genuine personal care for the individual.

When caregiving is only financially incentivized, care recipients feel more like a burden rather than human beings. Employees often have a harder time getting care recipients to comply because of the lack of trust and continuity in their relationships (Allen and Ciambone 2003, 215). When caregivers for mentally disabled adults work eight-hour shifts at a time, they merely need to tolerate any lack of cooperation until they are free to go home, be with their loved ones and friends, and enjoy their free time; however, house parents in Sassen cannot escape to their separate personal lives because their role as caregivers is their personal life.

They have to foster their relationships with the villagers and allow trust to build – to figure out what unique needs each individual requires

to be fulfilled in order to feel safe and comfortable enough to comply. If a villager is particularly reluctant to cooperate or even hostile, it can become disruptive to others in family. However, it is important to recognize that such behavior is often indicative of either a lack of trust between caregiver and villager or of a neglected need or discomfort experienced by the villager. As a result, it also becomes in the best interest of house parents and everyone involved to take a more personal approach and get to *know* the villagers and let the villagers get to know *you*, as opposed to simply tending to their basic needs of food and hygiene. The more time you spend with villagers, the easier it becomes to establish not only trust, but also a friendship, which makes tasks like bathing and cleaning much more pleasant and easier to undertake for all parties involved. In essence, reciprocal closeness, trust, and respect is essential to the villagers' acceptance of care (Allen and Ciambone 2003, 214). By facilitating this inseparability of practical and emotional labor through live-in care, Sassen achieves a level of caretaking incentivized by familial empathy and duty rather than money. Furthermore, this model gives villagers agency in their own caretaking by making the relationship between caregiver and care-recipient one of reciprocity and dignity (Aronson and Neysmith 1996, 65-67).

There were a few days in a row where a villager named Klaus would scream and bite his finger very frequently, and we did not know why. Not only did this indicate his unhappiness, but it also drove other villagers to act out, and disrupted all of our sleep at night. Klaus does not talk to people directly, but thinks aloud in often confusing, random, and repetitious statements. After careful observation, I noticed that his bowel movements were irregular and that his frequent random mumblings mostly referred to his bowels. We concluded that he had stomach aches, so we altered his diet slightly. Sure enough, he stopped talking about his bowels as they became more regular. I was only able to discern this, however, because I was the only person taking care of him for a longer period of time. If his caretaker were to switch every eight hours, they might not be bothered by his screaming or not even notice his irregular bowl movements and mumblings.



Working in Sassen only weeks at a time once a year has made the importance of continuity in relationships between care recipients and caretakers all the more obvious. In the summer of 2016, I was responsible for Klaus and Ben. I had taken care of Klaus for five weeks straight two summers before, but had never even met Ben before. On my first day back, I encountered no issues getting Klaus ready in the morning, although we needed to get used to each other again. He had a look of confusion on his face when I woke up him up and was initially hesitant to get out of bed; however, I knew exactly what to do when getting him ready in the morning. He does not shower on his own, but he likes to take the shower head and play with it. He brushes his teeth on his own, but will not do it until someone puts tooth paste on the tooth brush for him. He does not dry himself off very well, but will stubbornly insist on taking the towel. Because I was familiar with him already, I knew to let him have his fun with the shower head, put tooth paste on the tooth brush, and indulge him with drying himself off before I do a more thorough job. Otherwise, he would not comply. At the beginning of my first summer with Klaus, I took his towel to dry him off after a shower, but he started tugging on it. I resisted and tugged back because I knew he could not dry himself properly. Eventually, I learned to accommodate him, and everything went much smoother from then on. Because of our previous acquaintance, I had a smooth transition into the summer of 2016; however, despite that, he initially demonstrated hesitance because he had been used to his house father as a caretaker for most of the last six years, not me, and required time to adjust to having me as his primary caretaker. Although I had taken care of him before, whether or not he remembered me was unclear. I merely knew him well enough to ensure his approval of my level of care.

I had a rocky start with Ben. On the first morning, he walked to the toilet and sat down. I waited until he stood back up, and I looked into the toilet to see if he had defecated. He had and so I helped him wipe. Once he was naked getting ready to step into shower, however, he defecated onto the floor. I immediately sat him back down on the toilet and cleaned up the mess. The next day, when Ben stood up from

the toilet and there was nothing in the toilet bowl, I lightly pushed down on his shoulders, encouraging him to sit back down on the toilet. Sure enough, after a few minutes he began to defecate and there was no mess. Eventually, I learned how to care for him best like I had with Klaus two years before. For example, Ben liked to hold my hand on walks and would be upset if I did not, unlike Klaus who liked to walk alone ahead of the group and would get agitated if I coddled him too much.

Routine and continuity are very important to the villagers. They need to know whom they can rely on, trust, and look to for help. While the continuity of a few weeks at a time has helped me develop trusting relationships between villagers and myself, my absence during most of the year resulted in limitations of my ability to calm them down on a bad day. When I first stayed with house mother Julie, I was originally supposed to help Erik get ready in the morning. When I walked in the first few days, he refused to get out of bed until I called over Julie and she sternly ordered him to get out of bed if he wanted to eat. Knowing full well that she was the one actually in charge, he reluctantly got out of bed. Julie knew that his stubbornness would not change in the short three weeks I was there in 2015, so she reassigned me to Jakob who is much more compliant and trusting.

If caretakers were to switch on a daily basis or every few hours each day as it does with shift-based work, then villagers would not know who they can rely on at any given time. Trust between villager and caretaker would develop much more slowly and would lack a personal touch. According to Caroline, caretakers at her old job had lots of issues controlling the residents as a result of the inconsistency and lack of empathy in those relationships.

Of course, issues found in traditional institutional settings cannot only be attributed to their shift-based labor model; certainly, there are shift-based caretakers who develop close, trusting relationships with care recipients as well. However, live-in care helps encourage and facilitate those types of relationships more organically and easily. Furthermore, Sassen incorporates *multiple* practices – not just live-in care – into its model which help eliminate other

issues found in traditional institutions. The community assigns the villagers meaningful social roles and provides them with agency and freedom. Thus, this combination of Social Role Valorization and the Social Model in *addition* to the familial and personal touch of live-in care allows Sassen to further empower and humanize the disabled community (Allen and Ciambrone 2003; Hughes 2011; Wolfsenberger 2011). While shift-based labor models are not solely responsible for all issues found in institutional settings, traditional institutions tend to fail to incorporate these other important enabling practices, too.

## **Empathy and Kinship**

Sassen has overcome such issues of inconsistent relationships between workers and villagers by providing the villagers with live-in house parents, engendering new notions of kinship. Because villagers are unable to care fully for themselves as adults, Sassen provides the villagers with a surrogate family that will endure throughout their adult life, even when their guardians or parents can no longer care for them. These surrogate families become as real to them as their families back home, for they spend most of each year in Sassen – eating meals, working, and spending free time together in Sassen. Living together in these initially makeshift families eventually engenders a real familial atmosphere in which villagers and house parents alike feel as comfortable, connected, and communal as any traditional family would. In some cases, in which a villager no longer is in contact with their family back home, their family in this community becomes their only one. In regular shift-based homes, once their parents pass away, many disabled individuals lose much of the empathy, love, and emotional connection that their home life had provided. However, Sassen is indeed a place they can call home, a place where they have family, love, and empathy – not just a place where they are being kept to survive.

## **House Parents, Parents/Guardians, and Villagers**

While Sassen provides its villagers with care that emulates the love and empathy they had at home, these surrogate families can create tension between the guardians and house

parents of villagers whose families still remain in contact with them. After a villager spends years in Sassen, it becomes ambiguous who actually knows the villager better and who knows what is best for that villager – the house parents or the biological parents. The guardians – often parents or siblings – sometimes claim to know the villager better than the house parents because they grew up with or raised them during their formative years; however, just like in the abled community, mentally disabled individuals change as they grow older, as do their needs. Their house parents who have spent many years with them are present as these changes occur, while their guardian only sees them a few weeks per year at most.

Many parents fail to see that living in a community is very different than living at home with family because one needs to be able to share attention much more than in a small family. The biological mother of former villager Hans – a villager whom I took care of my first summer in Sassen – was adamantly involved in her son's life, welfare, and treatment, claiming to know exactly what Hans needed and how he should be treated. It became very quickly clear that Hans not only desired a lot of attention, but required it in order to feel content. One morning on our daily strolls around the farmland, Hans and I walked arm in arm as we always did, and Klaus walked ten yards ahead as he always did. Since Klaus does not react to verbal commands, I had to run up to him and hold his hand so that he would stand still once the distance between him and the rest of group became too big. Upset that I left his side, Hans started sprinting right past me. In effort to catch him, I ran after him and stopped him as I did with Klaus. Clearly angry, Hans hit me across the face and started kicking me. Other times when I tended to other villagers, he would throw his mug on the ground and throw a fit. By its very nature, a community is about sharing attention and giving it where and when it is needed. At home, his parents could give him all of the attention he desired; however, I as an intern, as well as any other coworker, could not possibly provide him with constant attention when other villagers needed their food to be cut or needed to go to bathroom.

Nonetheless, Hans' mother disapproved of Sassen's treatment of her son. We eventually learned that Hans liked to take out his frustrations on the pictures and books in the room in which he was staying – a room that belonged to another villager who was on vacation. Once, he cut himself accidentally on the glass of a picture frame he broke. We took everything out of the room in order to prevent him from hurting himself and continuing to destroy another villager's belongings. Upon asking Mark recently what happened to Hans, he told me that Hans' mother took him out of Sassen. In preparation for his stay one winter vacation, Mark removed everything from his room except for the bed. Upon arrival, Hans was hesitant to leave his mother's side once he realized that he was meant to stay there. As a result, his mother felt uneasy about leaving her son unhappy and asked to see his room. Upon seeing the bare room, she accused Mark of inhumane treatment and took Hans back home. She had expected that her son would receive the *same* familial treatment as he had back home. While Sassen does provide familial support, the families reflect different notions of kinship. They are very large and communal, unlike Hans' family, where he was an only child. Hans was accustomed to individual, one-on-one care, which Sassen, as a community in which attention must be shared, could not provide.

There are also cases in which the surrogate family with which a villager is provided becomes the only family that a villager can rely on. Maia, a very small, elderly villager with Down Syndrome, was supposed to spend just one week at her sister's house in the middle of the summer vacation. Maia requires a lot of care, including showering, changing diapers, and brushing teeth. Extremely excited, Maia jumped up and down laughing when her sister came to pick her up. Expecting her to come back a week later, we were surprised to see her dropped off alone in a cab just a few days after she had been picked up. After asking Mark about this incident, he said it was unfortunately not uncommon for a villager's family to send the villager back early because they could not or did not want to deal with the trouble anymore. I could not help but feel incredibly upset by this incident, though. Maia cannot speak and is very small; she is defenseless, and

her sister had left her alone in a cab with a stranger. Maia cannot even rely on her sister to fulfill her needs. Sassen is the one place she will always be provided with care; thus, in cases like these where a disabled individual does not have a reliable family to fall back on, it is vital that communities like Sassen provide them with empathy, care, a true sense of belonging, and a new family.

## The Role of "Die Lebensgemeinschaft e.V." and its Future

"Die Lebensgemeinschaft e.V." of Sassen and Richthof has given back to the disabled individuals what modern society has taken away from them: their humanity. The modern world has developed without considering the human needs of those with disabilities. We marginalize them as something other than human and isolate them to an existence that merely consists of survival. Rather than acknowledging them as fellow members of the human race with the same abstract emotional needs that separate us from other animals, society uses their cognitive differences as an excuse to disregard the existence of those needs.

Inspired by Karl König's original Camphill community in Scotland, Sassen provides them with this purpose (Hart and Moneteux 2004, 70). The families, the workshops, and the community give them something to live for: love, empathy, friendship, and family. Every villager's job serves the greater community in some way. The gardeners and farmers harvest vegetables for the families to eat. The woodshop, ceramic, and textile workers produce furniture, dishware, decoration, and fabric for the community to use and for the shop to sell to members of mainstream society. The household workers help maintain a clean living space and cook the food. Everyone's role helps sustain this community. Sassen allows the villagers to express their humanity in a safe space. "Die Lebensgemeinschaft" – this *living* community – not only gives them a greater sense of purpose, but also the freedom to have human experiences, to listen to music, to create art, to play a sport, to love, to laugh, and to belong.

It is a true testament to the employees of Sassen to have made this community possible. They refuse to believe that the image of humanity that modern world issues paints truly reflects our nature. As long as their idealism endures, so will their community. In Mark's opinion, the moment they stop believing in the community, it will all fall apart. The cornerstone of the community's ideology is one that *requires* idealists: everyone should give what he or she can, no matter how much or how little, and everyone should receive what he or she needs, no matter how much or how little. Similar to Karl König's vision of the ideal Camphill community, coworkers and villagers alike work and receive varying amounts based on what they can do and what they ask for or require. Obviously, a villager unable to carry out basic tasks will receive more from the community and give less in return (Christensen and Heyer 2004-2005, 27).

This also applies to coworkers. Mark comes from outside the country, and takes his family to his home country once a year; however, he also acts as a substitute for house parents whenever they need a few days off for various reasons. Therefore, their strong communal mentality does not take salience over individuality, but nurtures it. They acknowledge everyone's unique needs and do their best to fulfill them. Reflecting a communist-like mentality, questions of abusing the system arise. Indeed, there are always people who abuse such a system and profess more needs than they actually have – workers who take many days off or steal from the food supply, for example. However, as long as workers give enough back to the community, such abuse is forgiven. For example, as long as the family dynamic and welfare of the villagers are not harmed in any way, house parents can take “unnecessary” days off every once and a while.

The idealism to see beyond the minimal abuse of this system is vital to the survival of the community. Once jealousy and petty comparisons of work effort bleed into the ambiance of the community, workers will fail to see the greater result of their work and feel that it is not the worth the effort anymore. Because the house parents of Sassen and Richthof continue to trust in humanity's kindness and

selflessness rather than the individualism and materialism we often see in modern society, they are able to do what the mainstream society has failed to do: to create a community that not only gives disabled individuals their humanity and freedom back, but also believes in the goodness of that humanity, and provides help to all who need it.

## Conclusion

In providing mentally disabled adults with surrogate families that emulate the loving, empathetic environment of their biological families, and in some instances even become the only family villagers have left, Sassen's model of care demonstrates the importance and effectiveness of alternative forms of kinship. In their classic works on alternative forms of families, anthropologists like Carol B. Stack often refer to the rigidity of mainstream society's accepted notions of kinship, which are mostly limited to the idea of the nuclear family (Stack 1975, 126-127). In her account of personal kinship networks in low-income African-American communities, Stack debunks stereotypical conceptions of unstable kinship structures in black communities. Unlike in the nuclear family, personal kinship patterns in the black community in which Stack studied extend well beyond the biological parents of the child. While the majority of mothers raise their own children and have extremely strong bonds with them, their kinsmen often “anticipate the help they may have to give to young mothers and the parental responsibilities they may have to assume toward the children of kinsmen” (Stack 1975, 48). Stack finds that these kinship networks – unlike commonly perpetuated stereotypes – are extremely stable and effective among poor blacks because the challenges of poverty remain constant and severe (Stack 1975, 54).

Barbara Myerhoff demonstrates another form of kinship that exists outside of mainstream society in her classic account of culture among Jewish seniors in Venice, California. Myerhoff attributes the strength and resilience of the Jewish community to the kinship that they feel with another through their common history of persecution and suffering (Myerhoff 1978, 217-219). Upon the death of one of the Center's members, the

kinship that existed between Jews at the Center became clear in the mourning rituals that followed. One person pulled out the hem of her dress, another laid a scarf over a mirror, and someone else poured a glass of tea into a saucer – all of which are Jewish mourning traditions. The death was heavily discussed by all members of the Center as a proper Jewish death, in the community amongst fellow Jews rather than in a hospital with strangers (Myerhoff 1978, 214). Although the Center members were not biologically related to one another, they all mourned this death as if a member of the family had been lost. This form of kinship is rooted in history and culture rather than the mainstream conception of the nuclear family in which kinship is typically limited to parents and their children; and yet, it proves to be as emotionally sincere and powerful as conceptions of family.

It is vital that future research continues the work of such anthropologists as these on alternative forms of kinship, their legitimacy, and the importance of their role in providing those excluded by mainstream society with the community and empathy that all humans yearn for. Mentally disabled adults do not quite fit into mainstream conceptions of family, but that does not mean they do not need or yearn for the love and community that kinship provides. Acknowledging this need, Sassen highlights the ways in which society's limited conception of kinship allows its non-normative members to fall through the cracks, often left to institutional care that fails to engender a personal atmosphere.

Society too often sets rigid standards of normativity that marginalize members who fail to meet those standards, whether it is mentally disabled adults, low-income African-Americans, or elderly Jews. Along the lines of the works of Stack (1975) and Myerhoff (1978), future research should seek out other communities on the fringes of society and shed light on more alternative forms of kinship that need to be legitimized in greater society because humans need family – and that comes in all different forms.

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