

## Creating Participatory Space through Partnership

Exploring the relationship between a faith-based day programming organization and a cohousing community for individuals with and without disabilities

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## **Abstract**

This thesis examines the relationship between a cohousing community and a related ministry center in a mid-Atlantic state that seek to encourage an environment for people—with and without disabilities—to live together while fostering the individuality and autonomy among members of both groups. This thesis explores how these two organizations attempt to create space for individuals with disabilities to exercise personal agency and independence, as well as encourage mutual relationship building between persons with and without disabilities. The implications of their partnership were the central focus of this inquiry.

The analysis investigates how the physical structures, locations, and accessibility of formal and informal spaces for people with and without disabilities residing in the cohousing community create opportunities for their visibility and exercise of agency. It also outlines the structure and aims of the nonprofit that collaborates with the cohousing community, as those relate to agential possibility, including the role of personal development through a faith-based identity. Overall, the thesis employs Iris Marion Young's framework for inclusive democracy to explore the effects of the combined efforts of these two entities for the perceived agency and autonomy of a sample of residents with disabilities participating in both (Young 1990, 2000). In particular, this analysis explores the central tenets of the two nonprofits' organizational cultures as those relate to political agency, by sharing the findings of semi-structured interviews with residents, staff, and board members about their experiences as a part of each institution. The analysis also details the primary features of the physical environments each FBO has

created and their implications for the perceived agency of a sample of those residents with disabilities involved with both nonprofit organizations. It offers insight into the importance of identity, equal inclusivity, and opportunities for expression in formal and informal settings for the encouragement of agential possibility. The results of this study indicate that the relationship between the nonprofit and cohousing community has allowed individuals with and without disabilities the opportunity to take ownership of their friendships and relationships, including their relationship with God. This suggests that the role of faith in this community provides individuals with disabilities a chance to express agency over their personal faith life as well as their goals and ambitions. Individuals without disabilities in this community encourage this personal agency because of their own definition of personhood as understood through Christian faith.

This inquiry was based on 12 semi-structured interviews with staff, governing board members and participants involved with each entity investigated as well as review of their websites and relevant documents concerning their visions, missions and goals.

### **General Audience Abstract**

The purpose of the research was to explore the relationship between a faith based day programming center for persons with disabilities and a related cohousing community, and how these two entities provided individuals with varying degrees of disabilities with opportunities to express personal agency and personal development. This inquiry was based on 12 semi-structured interviews with staff, participants, and governing board members as well as a review of these organizations' documents concerning visions, missions, and goals. The results of this research indicate that these communities provide individuals with disabilities a chance to see themselves as important to society and ultimately to God. Opportunities for these experiences, according to participants in this study, stem from a place of Christian faith.

## Dedication and Acknowledgements

First and foremost, I would like to thank the extraordinary individuals that participated in this study for their honesty and openness. You all have inspired me in so many ways, and I am so thankful for the opportunity to share a bit of life with you. To “Nicole” and “Lyth” especially – thank you for providing me with the idea for this study, and for all of the remarkable things you do everyday to prove to the world that every person has value, and every person brings something beautiful to the world. Your lives have transformed my own. This thesis is dedicated to you.

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And finally, to the One who knew from the beginning that my circuitous academic and professional life would eventually lead me to this research, and who will hopefully use my life and this work to demonstrate His great love:

*“Christ Jesus came into the world to save sinners—of whom I am the worst. <sup>16</sup> But for that very reason I was shown mercy so that in me, the worst of sinners, Christ Jesus might display his immense patience as an example for those who would believe in him and receive eternal life. <sup>17</sup> Now to the King eternal, immortal, invisible, the only God, be honor and glory forever and ever. Amen.” 1 Timothy 15-17 NIV*

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## **Chapter 1**

### **Introduction**

I became involved with the organizational partners analyzed in this effort in 2014 when I moved to the state where the institutions are located after completing my bachelor's degree. I found that there were many young adults in the area that felt adrift — they lacked opportunities for engagement, participation and meaningful relationship building. Through a friend, I was introduced to a volunteer opportunity at a local ministry center that worked with individuals with disabilities. Through that experience, I witnessed how that organization worked to encourage meaningful relationships with and among those it served by building spaces and opportunities for individuals with and without disabilities to be as engaged as feasible with their environments and to experience a communally focused sense of efficacy and belonging.

One of these spaces was the cohousing community in which many of the individuals lived or spent time. People with and without disabilities residing in the community enjoyed one another's front porches, playing basketball at the communal hoop, working in the community garden and sharing drinks and dinner at the local restaurants nearby. Because of its location downtown and its accessible design, I began to wonder if this approach—combined with the message of inclusion promoted at a partnering ministry center and its day-support program nearby—encouraged participation by those with disabilities in the decision-making processes of the two organizations. The trajectory of the disability rights movement in America suggests that this partnership might be an appropriate one for study. Recent research and policy has focused on providing opportunities for people with disabilities to become more engaged in civic life,



rather than secluded in living environments surrounded only by other individuals with disabilities and paid caretakers. The deinstitutionalization movement has sought to bring people with disabilities into communities and non-exclusionary home environments that provide them the health and welfare services they need, while also underscoring their need to be involved in decision-making processes and civic activities that affect their everyday lives (Ewing 1979). However, individuals with disabilities still exhibit very low voting rates and participation in formal governing body processes and activities. This fact led me to question what opportunities for participation existed in the two organizations in which I became interested, how individuals engaged in those activities and what strategies of inclusion, if any, were practiced by the two entities that encouraged the exercise of agency by those people with disabilities involved in them.

My interest in exploring whether and how such opportunities were being created as well as what barriers existed to their creation in these institutions led me to explore the literature on inclusive democracy. Engaging with the work of Iris Marion Young (Young, 2000, 8) and her arguments concerning inclusion and participatory space led me to consider whether the relationship between the cohousing community and the faith-based organization I had discovered serendipitously, in fact presented an opportunity for fulfilling Young's vision of inclusion. Young's work prompted me to examine the importance of social and physical spaces as mechanisms to encourage individual agency. I saw in the partnered organizations I had discovered an opportunity to study in greater detail whether environmental and program design could work together to encourage opportunities for individuals with disabilities to recognize and act on their innate capacity for agency. Figure 1 offers a map of the community where the nonprofit organizations I

studied are located (outlined in red) and the immediate neighborhood surrounding them.

Table 1 outlines the relationships among the various group homes in the neighborhood, and their relationships with New Growth Ministries or the Second Avenue cohousing community.

**Figure 1: Map of immediate neighborhood surrounding Second Avenue. Boundaries of Second Avenue are indicated in red**



**Table 1: Relationships between entities. Edges House is both a subsidiary of New Growth and located in the Second Avenue Neighborhood**

Entity Name	Sub Entity	Operated by	Activities occurring at this location
New Growth Ministries		New Growth Ministries Staff and Board	Day programming, evening activities and programs, community worship
	Edges House	Partnership between New Growth and Second Avenue	Homegroups (partnership with New Growth), community language classes, community dinners, informal get togethers
Second Avenue		Private HOA	Formal monthly gatherings, informal get togethers
	Agape House	Partnership between Second Avenue and Local Divinity School	Largely private activities with Agape House residents
	Edges House	See above	See above

### **Research Synopsis and Study Aims**

To explore further the relationship(s) between New Growth and the Second Avenue cohousing community, I conducted semi-structured interviews with 12 residents-participants, staff and board members of the partnered FBO and cohousing community. Interviews lasted about 45 minutes on average and addressed questions developed on the basis of Young’s framework concerning the conditions necessary to ensure individual exercise of democratic agency. I asked interviewees to discuss the programs and spaces for which they are responsible or in which they participate in an effort to understand better whether and how those encourage individuals with disabilities to participate and express personal agency. I designed these questions to be largely open ended to allow individuals to share their own thoughts in detail, so that they could describe, in their own

words, how their role(s) in the organizations affected them.

## Chapter 2

### Literature Review

#### COHOUSING

Cohousing is a form of residential development that aims to create communities with a high degree of relationality by creating formal and informal spaces for resource sharing and social interaction (Bouma and Voorbij 2009, 2). Cohousing has existed for many years in European countries, especially the Netherlands, but is a relatively recently employed form of community in the United States (Bouma and Voorbij 2009). These developments are generally structured legally as homeowner/condominium associations, with individuals paying dues to a common fund that is managed by an elected volunteer group of owners and that provides upkeep and maintenance of common areas.

Individuals residing in cohousing generally own their homes and the relevant homeowner's association owns the land on which their houses are situated. Individual residents of the cohousing neighborhood I studied also covenant within this legal structure to be active members in the social life of their community, as well as to provide assistance to their fellow residents with disabilities when the need arises. This includes both formal and informal opportunities—for instance, participating in a group activity or dinner, as well as offering transportation to residents with disabilities who cannot drive.

The physical design of cohousing communities seeks to create opportunities for formal and informal interaction to encourage relationships and “life sharing” among residents. Those interactions in turn help to build trust among neighbors, encourage additional exchanges and build social networks (connectedness) and common rules/norms (Pretty & Ward, 2001). Cohousing creates both private and commonly

owned property; resulting in purely private, semi-private and communally shared spaces. Assuring private space provides residents opportunities to express autonomy and ownership concerning their personal residences; they may retreat to this domain when they need to be away from others and they enjoy complete purview concerning who is allowed to enter it. This area provides owners a degree of personal independence and privacy— something that individuals with disabilities are often denied.

Cohousing's semi-private spaces include porches, sidewalks and connected yards and green areas. These are technically part of privately owned residences in many co-housing developments, but because of their visibility and salience often become prime spaces for informal activities and interactions as well. These places afford residents opportunities to invite a neighbor for an outdoor game, a cup of coffee on the porch, or to offer a casual hello and opportunity to share community news. Residents initiate these opportunities. That is, nothing about co-housing design or practice requires that if an individual sees a neighbor or neighbors approaching on the street, he or she must engage with them. This allows inhabitants to determine the extent to which they wish to be sociable at any given time. For individuals with disabilities, this creates opportunities to determine whom their companions and trusted friends will be in a way that allows them to make those decisions, rather than being forced to participate in any specific setting (Brown and Brown 2004). It creates opportunities for individuals to initiate conversations with those with and without disabilities in a context that encourages equality between them. This structure is unique not merely for persons with disabilities, but is also largely absent from traditional neighborhood design. Cohousing models an understanding of hospitality that contrasts with the “modern capitalist economy [that] leads people to

detach themselves from the concrete places and communities that constitute their lives” (Newman 2007, 76). In cohousing, people are encouraged to feel grounded and invested in the physical and emotional spaces in and near which they live.

Both persons with and without disabilities live in the cohousing community I explored, and they shared certain resources and interests by dint of living in a cohousing development. The fully shared areas found within cohousing neighborhoods aim to provide residents with opportunities to engage in communal decision-making (Pottie and Sumarah 2004). These spaces can include gardens, common buildings, and recreational areas, such as basketball courts or swimming pools, as well as picnic locations. These locations may be used by anyone in the community, and while they can generally be reserved for certain events, they are almost never off limits to any resident. There are also spaces in which cohousing community residents generally make formal decisions and therefore must be completely accessible to everyone in the community. In the cohousing development I studied, these areas were fully accessible for individuals with mobility impairments, as well as free of things that may have rendered individuals with sensory impediments unable to participate in group activities conducted within them (Brown and Brown 2004). According to Young, such accessibility must also include opportunities for sharing thoughts and concerns with other residents (Young 2000). Because these spaces are commonly owned in cohousing developments, their access to all implies that every person has an equal say in the governance of the community (Pothier and Devlin 2006). This creates one way of combatting what Young has described as the ‘articulativeness privilege’ often found in communal decision-making. In Young’s view, to be democratically participatory, individuals, regardless of ability and way of

communicating, must have an equal say in the governance of a community (Young 2000, 48).

Those creating cohousing communities generally try to locate them in urban areas that are also connected to the larger region in order to widen resident opportunities for formal interaction through participation in neighborhood councils or citywide events, as well as informal contacts, such as eating or having a drink with a neighbor at a local restaurant. This arrangement seeks to ensure that cohousing developments are not isolated and do not present as anachronistic microcosms of socially just societies (Kirkpatrick 2001) The compact living conditions of cohousing communities also improve accessibility for individuals with disabilities. They are able to move about their neighborhood more readily when distances to needed facilities and amenities are shorter, as well as obtain services and resources offered by the city in which their neighborhood is located, such as transportation and healthcare, without undue hardship or difficulty, since these are often located nearby.

Urban locations also create a sense of integrated-ness rather than isolation relative to the rest of the broader community—cohousing neighborhoods are not meant to be isolated from the rest of their environment, but rather intended to be communal social and living environments within the larger jurisdictions in which they are situated. By sharing activities and the ‘daily rhythms’ of the neighborhood with one another, cohousing residence creates a mutual “dedication to relationships of acceptance” (McDonald and Keys 2006, 12).

Small groups provide a support network and the ability to develop interpersonal ties, but they do not alone provide the level of autonomy needed for individuals with



disabilities to recognize their needs, desires and goals for life in the larger community (Kirkpatrick 2001). Cohousing developments located in close proximity to public spaces and events create opportunities for individuals with disabilities residing in them to exercise agency in their environments, in addition to doing so alone within their homes and communities. Participating in the councils, organizations, festivals and rhythms of the city can provide individuals with disabilities with a sense of ownership and responsibility for the larger community of which they are a part. Cohousing is designed, first and foremost, to inspire social and relational interactions. As Kirkpatrick has argued,

A good community, one that truly fosters human flourishing, requires a degree of pluralism, democracy, and an encouragement of diversity (given the complexity of human nature as it manifests itself in various social groups) in order to foster the very conditions that make a community vital, exciting, and capable of growth (Kirkpatrick 2001, 90).

Cohousing emphasizes the idea of “life sharing,” an orientation that aims to create communities in which residents rely on one another, and share physical, social and emotional events and experiences with other residents. In the community I explored, life sharing was intended to create an environment in which individuals with disabilities can live independently and direct their lives as autonomously as feasible, but with a ‘safety net’ of friends and neighbors aware of their unique needs and willing to support them without formally becoming their guardians or caretakers (Kirkpatrick 2001, 90).

Individuals with disabilities are also expected to share responsibility to ensure that their neighbors are not disrupting communal life, and to help in any way they can when challenges arise. Ideally, cohousing design and operating premises encourage residents genuinely to care for one another, rather than see their neighbors as a burden or act of charity. As Newman has argued, focusing on the relationships between individuals rather

than quantifying what a person can provide to another or to the community is unique because of the trend in American society to consider the home another place of consumption analogous to the economic market, leaving little space or regard for persons who cannot contribute in a monetary way (Newman 2007,77).

In this regard, it is important to stress that residents of the community I examined have expressed a commitment to living in the “economy of God rather than the immanent economics of the modern marketplace,” which orientation aims to dignify those who have been historically ostracized by providing them with spaces for growth and opportunity (Newman 2007, 77). To the extent these communities’ design and operation axioms succeed, they help foster an atmosphere of collective as well as individual dignity; individuals are important in and of themselves, and they must be allowed to make their own choices, but they are also of vital importance to the collective character and possibility of the community. Residents should not be left out of decision-making, nor can their concerns or ideas be considered less significant than those offered by others in the community if the aspirations of cohousing are to be fully realized.

As mentioned above in the discussion of cohousing’s semi-private spaces, opportunities to develop mutual accountability among residents arise through both formal and informal connections in such neighborhoods. Cohousing developments create spaces for individuals to come to know one another, share information and support or assist each other with problems. This community also attempts to create places for individuals who previously had little authority over their lives to play formative leadership roles in the community, which gives them a chance to rethink their own positions in both the mediated spaces of Second Avenue and New Growth, and the community at large, a

reflexive aspiration and a central aim for Young (1990, 56). Formal activities include regular meetings and shared meals, and these, by agreement, must include the entire community or at least a very large percentage of its members. Informal interactions create opportunities for one-on-one relationships to develop.

Organized events and governance activities create possibilities for another of Young's criteria for democratic possibility to occur: formal acknowledgement. Individuals with disabilities are often overlooked, left out or patronized by residents offering activities in the broader communities in which they live. When they do participate in those events in their towns, their engagement is rarely accorded the same standing as those without disabilities. In principle, and, at their best, in practice too, formal recognition of the contribution of individuals with and without disabilities in cohousing communities provides all individuals residing in them opportunities to exercise democratic agency and to develop group affinities and alliances that can help to address situations when individuals are not able to speak for themselves.

Cohousing's norms of association and discourse provide residents with status and authority and how they address and communicate with the less powerful with disabilities can have an important effect on the latter group's ability to participate in neighborhood events and activities. "Norms of Order," though not explicitly stated in many cases, may be so prohibitive of certain styles of communication that they effectively silence the voice of specific people or groups (Young 2000, 48). If individuals are not participating in accord with prevailing norms, their arguments may not be considered serious or even rational in some instances. Statements regarding a person's capacity to participate may even be raised. More powerful actors may, "imply that one's opponents are less than

human or that their views do not deserve an equal hearing because of who they are” (Young 2000, 48). Exclusionary strategies can be internal or external. External exclusion tactics that affect those with disabilities are often relatively obvious; there may be physical barriers to entry, such as multiple flights of stairs, locks, gates or even deliberate signs saying that certain individuals are not welcome.

Internal exclusion may be more insidious, but its consequences may be no less profound. Actions that keep people from sharing their thoughts—failing to accommodate people who do not speak a specific language: ignoring, belittling or talking over individuals or speaking to people using inappropriate language—can hinder the ability of those targeted to participate. These structures are often so ingrained in existing policies and standards that they have become, “conditioned by the specific structures and imperatives of American capitalism—structures of exploitation, segregated division of labor, and marginalization” (Young 1990, 122). To exclude someone deliberately from a discussion is to insinuate that their needs and concerns do not matter, and that they are not valuable as a person. Meaningful relationships, acknowledgement of diverse needs, as well as knowledge of others of whatever stripe, create the potential for trust in representation.

Cohousing’s focus on meaningful friendship creation in the community has the potential to encourage an atmosphere of equality not found in most other housing development types. Because there is not a caretaker/care-recipient dynamic in the community, individuals can be comfortable with another trusted resident to represent their needs when they are absent or unable to contribute for any reason (Brown and Brown 2004). Caregivers who receive payment for services are held to legal requirements

that may not allow them to be comforting or caring in a way that an unpaid friend can be (Brown and Brown 2004). At least as an aspiration, all that limits individuals with disabilities living in cohousing developments from creating and sustaining a strong web of friendships are their own capacities, interests and disposition to reach out to others.

When these attributes align, they can help to break down the physical and emotional exclusions many people with disabilities have experienced throughout their lives (Brown and Brown 2004). For the cohousing community I studied, its commitment to a Christian theory of hospitality required that such barriers to inclusion be identified and addressed, often through conversation, friendship and understanding, “ourselves as both guests, receiving from the other, and hosts, offering ourselves to the other. For example, a person who is mentally handicapped is not simply deficient but can have gifts that might well transform our lives” (Newman 2007, 144). At its best, the primacy placed on relationship building within cohousing communities can create a neighborhood in which decisions that affect all residents are made with everyone’s input.

As I noted above, although much is shared in a cohousing community, private ownership of homes creates opportunities for independence for residents. All individuals also have control of their finances and, to a large extent; their day-to-day lives separate from others in the community. They are able to make their own decisions about their jobs, spending habits and home environments without interference. However, they also accept a communal responsibility to ensure the safety and welfare of their neighbors. When the relationships among neighbors are meaningful ones, this responsibility does not come across as a chore or a task. Rather, it arises out of love and mutual respect and is encouraged by the shared spaces and decision-making routinely practiced by residents

(and their Guardians and representatives, in the case of the neighborhood I explored).

## DEMOCRATIC AGENCY

Young has defined democratic agency as the inclusion of a heterogeneous population of individuals in decision-making for a select group or society, and the companion ability of each of those people to decide to participate (or not) autonomously in shared activities, rather than through the imposition of force (Young 2000, 8).

Inclusive groups and societies acknowledge all individuals within them, irrespective of their specific characteristics and they arrange for accommodations to ensure the participation of all, as they may elect, free of external impediments of any kind (Young 1990, 10). Democratic processes can be used to promote equality and greater autonomy for people with disabilities, because such processes, according to Young, “promote justice, call for widening and deepening democracy beyond the superficial trappings that many societies endorse and take some steps to enact” (Young 2000, 5).

When this condition is met, a heterogeneous population has input in the political processes of their community (whether group, neighborhood, town or other political jurisdiction). In this view, policy is only legitimate to, “the degree to which those affected by it have been included in the decision-making processes [affecting them] and have had the opportunity to influence the outcomes” (Young 2000, 6). This approach to inclusion recognizes and respects group affiliations and authorized representation. Processes that meet Young’s criteria attempt to address social inequalities that might otherwise bar individuals from participation (Young 2000). Ideally, such actions also ensure that participatory spaces are accessible to all individuals in the community. This is vital because according to Young, “rights are not fruitfully conceived as possessions, rights are

relationships not things; they are institutionally defined” (Young 1990, 25). For example, for cohousing neighborhoods, such processes would ensure that all residents or program participants have equal access to meetings, capacities to influence shared governance and entrée to common spaces. Cohousing communities, through their provision of areas for participation and efforts to encourage meaningful relationships, help to create opportunities for individuals to demonstrate democratic agency by promoting respect and equality among their residents, both in their governance and by means of their physical design.

When fully realized at any rate, individuals in cohousing communities assume (and presumably embrace) roles that promote a sense of neighborhood ownership and belonging among residents (Schiltz 2005). Democratic inclusion insures that, “all members of the given polity should have effectively equal influence over debate and decision making within that polity” (Young 2000, 8). For Young, the exercise of democratic agency implies individual shared interest in a common goal. Because cohousing communities are self-selecting, meaning that people choose to live there because they prefer the lifestyle they provide, their very structure implies a common interest. Cohousing encourages “respect and mutual obligation” among residents (Young 2000, 221). For the community to function, individuals must be willing to make decisions for the good of the whole, rather than simply in accord with their individual desires, meaning they must feel a sense of belonging and be willing to sacrifice for the best interests of the group when there is a need to do so.

This also means that power must be tempered for the dominant group, and understood as applying equally to each individual throughout his or her life, and to each

individual in respect to community decisions. If individuals live in situations in which a dominant group oppresses them, they cannot be fairly represented, nor can their interests be given proper consideration. Power, according to Young, cannot be ‘distributed’ per se, because it is formed and communicated through relations among groups of people (Young 1990, 34). Therefore, for a just society to develop, a community must have individuals who have a demonstrated commitment to one another, and have placed a primacy on responsible and informed citizenship.

Young also describes a distinct obligation to strive for justice as a tenet of a truly inclusive, democratic society. Such a culture, she has suggested, “requires a societal commitment to meeting the basic needs of all persons, whether or not they contribute to the societal product” (Young 1990, 91). This has profound implications for persons with disabilities who typically have been given very few opportunities for personal agency or inclusion in decision-making bodies in their communities. Importantly, Young contends that such exclusion makes many decisions that affect these individuals null and void. Justice, according to Young, “requires, however, participation in public discussion and processes of democratic decision making... Democracy is both an element and a condition of social justice” (Young 1990, 91). Communities must not only ensure that everyone participates in decision-making, but that they are given a representative voice on par with the dominant group as they do so.

Physical participatory space is also important to democratic possibility, according to Young (Young 2000). Places need to be accessible for all individuals in the community, and the timing and methods of communication must also accommodate differing member abilities. For example, the space should not be so large that individuals



seated in the back cannot hear or see what is going on at community gatherings, nor should it lack ramps or elevators for individuals with mobility issues. To avoid a prejudice toward elegant language, the governing body should accommodate individuals with different communication styles (Young 2000). For individuals with disabilities, this is particularly important as their contributions are often overlooked or disregarded because they may not verbally communicate within the expected norms of discourse. Inclusive space “requires openness to a plurality of modes of communication...inclusive political discussion should recognize and attend to social differences” (Young 2000, 12). Participatory places should also not be limited in what can be said within them (within the confines of civil discourse), or in who can use them.

Participation in these spaces can create opportunities for individuals with disabilities to develop a self-identity and affinity to a community or group unrelated to their disability (Vogel, Polloway, Smith 2006). Those with such group affiliations and identities should help to determine “who has the right to influence their operations and who does not” (Young 2000, 13), including both individual goals and the workings of the entities themselves. These associations provide people within the community the chance to develop skills such as public speaking, networking and argumentation in a safe and respectful environment. These capacities may be developed in formal and/or informal contexts. Formal gatherings or classes, such as those offered at the FBO day program center whose operations I explore below, can provide lessons and practice opportunities for individuals to work on developing such capabilities, whereas the cohousing community can provide group participation and problem-solving experiences. These possibilities can have a tremendous impact on the degree to which individuals with

disabilities may be able to pursue more or less autonomous lifestyles suited to their capabilities. Seeing their value to a community as well as their ability to make changes and contributions to their environments validated can provide such individuals with the confidence to pursue goals and interests they might otherwise not have considered within their reach.

#### NONPROFIT-COHOUSING PARTNERSHIP

Both the cohousing community and the FBO I targeted for study are located in a medium-sized urban area in a mid-Atlantic state. While not legally related to one another, there is considerable overlap between individuals that live in the cohousing community and also participate in the FBO's day support program. This has created a highly integrated relationship between these entities that allows for the practical application of skills and achievements gained at the day-support ministry, in the cohousing community and vice versa.

Second Avenue, the cohousing neighborhood I investigated was established in 2012 out of a desire among its founders and participants (of an existing ministry's day programming services) for a safe, yet independent, living environment for individuals with a range of disabilities. As children with disabilities who had grown up in the city in which the FBO is located began to age out of the public-school system, their parents worried that the social lives of their adult (more than 18 years old) youths would be limited, and that they would not continue to develop or maintain the capacities necessary to continue to live independently. The hope of Second Avenue's founders, a large share of whom were responsible for children with disabilities, was that it would "serve as a

sanctuary and corrective environment away from the negative aspects of a competitive society” (McDonald and Keys 2006, 102). They envisioned a housing environment that would allow their adult children to live autonomously, but within a communal context that would meet their safety and social needs. Cohousing as a model, with its focus on community building and watchfulness without being overbearing or intrusive, fit this vision well. It also aligned neatly with the mission of the FBO to bring together individuals with and without disabilities in an environment of equality. In contrast to a traditional group home setting, the cohousing model provides a greater degree of autonomy and equality between individuals with and without disabilities.

The cohousing community is comprised of two homes that are owned by separate, but affiliated, organizations—Agape House, which is managed through a partnership with a local divinity school, and Edges—a recently opened facility, that is owned and managed by New Growth. Agape House ministries began in Michigan to address similar concerns of family members of adults with disabilities who desired a more independent, but supportive, living environment for their loved ones. Agape House Ministries partners these individuals with local divinity school students, and provides living spaces that encourage them to develop mutual, meaningful friendships. The individuals with disabilities residing at Agape House must be able to live in some degree of independence, such as being able to gain employment or volunteer work, and manage their own medication schedules. They must also be able financially to support the cost of living in the house. Agape House is located in the center of the street that divides the neighborhood North-South.

Edges House occupies the northwestern corner of the neighborhood. New Growth

purchased this home after receiving a proposal from current Agape House residents who desired a greater, more formal connection between the two entities. The home was the last to be developed in the neighborhood, and was opened to residents in January 2017. Edges houses three residents with developmental impairments, and four individuals who do not have any stated disabilities. The residents of Edges are all long-term participants and volunteers at New Growth Ministries. Individuals with disabilities were identified because of their commitment to and participation in New Growth, and because of their personal concerns regarding other available traditional housing options for people with disabilities, such as group homes. Because Edges serves as a formal link between New Growth and Second Avenue, New Growth sponsors a number of activities that occur in the home that are also open to the rest of the neighborhood as well as the larger community. Residents, many of whom are supported by non-resident individuals who agree to provide relational support and guidance to individuals living in the home, make decisions concerning their shared space during formal weekly gatherings.

As described above, the cohousing neighborhood's founders sought to use the development's built environment to encourage formal and informal opportunities for engagement. They recognized that individuals needed opportunities to express themselves, make decisions and become involved in social events on the basis of their preferences and values. Similarly, formal and informal participatory space is of great importance to Young's framework for democratic possibility. Both the FBO and the cohousing community have formally recognized the significance of offering occasions for participant/resident inclusion and engagement. This study explores the relationship of the two entities, and the ways in which each functions to provide opportunities that

encourage residents to exercise agency. So far as I am aware, this collaboration between an NGO serving individuals with disabilities and a nearby cohousing community also seeking to serve a share of the same people is unique in the nation. This analysis describes this special effort to provide disability support services that seek to focus on creating communities without neglecting individual autonomy, and maintaining independence (rather than providing services in the most economical fashion), while also charting whether the partnership's efforts satisfy Young's criteria for democratic agency.

## Chapter 3

### Research Design and Methods

#### THE STUDY'S FAITH-BASED ORGANIZATION

The FBO I examined was created in 2007 to provide a loving, communal space for individuals with disabilities as well as disadvantaged young people of the city in which it is located. Through an expressed, non-sectarian, Christian framework, the NGO began a series of social, educational and leadership training activities for its target populations with the overarching goal of creating meaningful relationships among individuals of varying abilities and backgrounds. New Growth Ministries began operating in 2007, after its founders' split with a large, national youth ministry over theological differences. Jeff, the husband of Margot, New Growth's executive director, had led that Ministry's program for a large region in the mid-Atlantic, and had been reprimanded for his teachings concerning the means through which individuals may obtain God's grace. This national organization's leaders argued that students should learn the Gospel by means of a highly structured program that emphasized the depths of their sin and how those transgressions disconnected them from salvation. The program was organized to encourage participants (high school and college adolescent students), to come to know the depths of their depravity and make a conscious decision to give up their sinful desires and build a bridge to salvation through Jesus Christ.

Jeff, however, argued that this approach left out those individuals who were incapable of coming to a full understanding of what separated them from God, and were thus not able to construct such a bridge. Such people, he contended, required an exception to the conscious decision required by the national organization. For Jeff, that

concern pointed up a number of problems that could not be addressed by means of the national ministry's understanding of Christ and salvation. For example, if individuals had to make a conscious choice to follow Jesus, how should program leaders determine who is capable of making that choice and who required an 'exception'? Jeff believed and preached instead that God loved participants even before they made a decision to follow Him and even if they never chose to follow Him. He described this differentiation as Theological Belonging as opposed to the national group's position favoring Practical Belonging that argued; "Believe and then you can belong" (Margot, Personal Interview, 2/21/2017).

Theological belonging, according to Jeff and New Growth's founders, implied that individuals already belong to the fold of God, and because of that love and acceptance, they innately possess the space and freedom to 'believe.' Jeff, along with the majority of the then national program's regional ministry staff, resigned over this theological distinction. As a result, the national organization chose to end its urban and disability ministry programs in the city in which New Growth is now located.

The founders of New Growth created their organization to fill the gap left by the national organization and the new FBO began offering after-school programming for at-risk youth at a high school located in the neighborhood. At the start, the disability ministry was the smallest of the NGO's programs, but as word spread amongst the disability community and area churches, the New Growth staff soon recognized a need for a relationship-based ministry for area persons with disabilities. The organization has since grown to provide daily programming that includes service projects and participant driven activities aimed at both fun and personal development. Regular offerings include

evening programs and periodic community-wide events, including a monthly worship service organized and offered by program participants.

The organization developed multiple options for involvement by its participants that ranged in size from large gatherings of up to 100 people on a given evening, to small Bible studies and “home groups” comprised of 7-10 individuals. These events occur at the FBO’s facility, as well as in private residences across the city, including in homes in the cohousing community I studied. Formal opportunities offered through shared decision-making within the community also helped provide chances for individuals to employ the skills and confidence gained during day-support programs. Participants are also encouraged to share their talents, stories, concerns and weekly highlights with the rest of the group at these events.

While legally two separate organizations, the lines dividing New Growth Ministry and Second Avenue are fluid—friendships formed at the FBO continue in the cohousing community and vice versa, as do the lessons learned and capacities acquired during day program involvement. The FBO, through the integration of “home groups” within the cohousing community helps to create formal opportunities for social interaction among neighbors in that development, as well as events such as hymn and carol sings that may be spontaneous and include any number of individuals at a given time. Life sharing, through these activities, helps to create a shared purpose or common goal, which Young suggests is one of the criteria for democratic agency. Individuals are encouraged through the relationships and skills gained at the FBO to engage more fully with the community in which they reside—whether or not they live in the nearby cohousing development. Individuals involved in the FBO’s programs frequent the surrounding businesses and



restaurants in the neighborhood, and regularly attend and perform at area church functions, the farmer's market and various citywide festivals.

### **Personal Orientation to Inquiry**

My approach to this research was largely constructivist. From my approach as a researcher, I came into this community with a rudimentary but preconceived understanding of the relationships between the two organizations, and of what their aims and goals were for serving persons with disabilities. I also began this study with my own personal faith that was considerably affected by my time spent with individuals in these communities. Recognizing that I have my own associations and experiences with this community, I actively sought to allow the individuals I interviewed to describe their perceptions of their organizations and environments and their associated meanings without my imposing my own or any other viewpoint. I sought to gain as detailed a level of knowledge of the organizations and of many of the persons living and working within the purview of the study as I could. To ensure I did not impose my own preconceived notions of community, I applied Young's framework for democratic participation, while also allowing individuals to speak freely about their own personal experiences.

In researching these organizations, I compiled each entity's governance documents, including mission statements, handouts for residents and potential volunteers, and news and essays written by staff regarding their participation in these programs. I also researched stories shared by respondents that referred to public events by crosschecking them against accounts in local newspapers or posted on local websites.

I included individuals with and without disabilities of varying degrees in this study. I asked participants who were under the purview of a legal guardian to have their

guardian present so that I could gain their consent as well as the assent of the participant(s) (as appropriate). However, as a matter of fact, I found that many of the individuals with disabilities willing to participate in this study had been granted guardianship over themselves. As a result, I did not have to interview individuals under legal guardianship as I had originally anticipated would be necessary.

To identify interviewees, I contacted the directors of the FBO, and they agreed to share information about this research study with their colleagues and program participants so as to assist me in locating possible study participants. Indeed, they compiled a list of potential interviewees for me that I then contacted using email, telephone, and social media connections regarding their possible participation in the study. At the time of initial communication, I presented each possible participant with information regarding the purposes of the study, what I would ask of them and what the risks and benefits of their potential engagement would be. I also provided them with a copy of the consent form via secure email prior to the interview so that they were able to consider it thoroughly before I interviewed them formally (assuming they elected to participate). From these original participants, I gained a snowball sample of additional participants through conversations with those original individuals about who would be interested in participating. A description of my participants and how they were recruited for this study appears in Table 2 below.

**Table 2: Interview Strategies and Contact Methods**

Group	Number of interviews	Contact method for interviews
Participants, volunteers and residents	7	Conversation with program staff, information provided at community / sponsored events, direct questioning via social media and email. Some of these individuals were identified as potential participants through conversations with other participants. They were then contacted using the methods above. Individuals were interviewed individually at a location they determined.
Program staff	3	Direct emails from research team. I interviewed staff individually at a location they determined.
Board members	2	Direct emails from research team, conversation and outreach from program staff. I interviewed Board Members individually in locations they determined.

I created pseudonymous identities for participants to protect confidentiality. The interview transcripts I prepared for each such session identify my interviewees only by their assigned pseudonyms. The key that links those pseudonyms to the actual identities of those I interviewed is located in a separate password-protected file on my personal computer, which is itself password protected. I have stored my interview transcripts and my field notes on the Virginia Tech Google drive system, and have password protected the same. All of this information is available only to the principal investigator and me.

I audio recorded all interviews and took diligent field notes concerning the context of each conversation and the body language and cues of those with whom I engaged as well. Participant comfort was extremely important to this study so as to obtain honest and forthright answers to questions that illuminated the unique nature of the organizations/communities and their partnership. I structured questions to encourage individuals to respond openly and thoroughly about their experiences and perspectives. I asked interviewees to choose a location for our interview with which they were comfortable and which they could access with relative ease.

Descriptions of each of the participants including their role in the community can be found in the table below.

**Figure 2: Interviewee Description Chart**

<b>Name</b>	<b>Age Range</b>	<b>Gender</b>	<b>Role in Community</b>
Carly	Young adult	Female	New Growth Staff
Mark	Young adult	Male	New Growth Staff
Michelle	Young adult	Female	New Growth Staff
Nicole and Lyth	Middle age / Young adult	Female / Male	Residents
Tom	Young adult	Male	Resident
Cormick	Young adult	Male	Resident - Edges
Rob	Middle age	Male	Resident
Carl	Middle age	Male	Executive Director - Agape House
Samantha	Young adult	Female	Resident
Lavender	Young adult	Female	Resident
Victoria	Young adult	Female	Resident
Margot	Middle age	Female	Executive Director - New Growth, Second Avenue Resident

I developed questions for my study participants on the basis of the criteria

identified in Young's framework for democratic possibility including:

1. Willingness to change views, and to put aside differences to attain an established or articulated "common good."
2. Deliberative democratic approach to decision-making that includes a multitude of voices and acknowledges varying perspectives, approaches and forms of discourse.
3. Respect for group affiliations and recognition of such identities and the influential nature of affiliation for individual and collective identity.
4. Recognition of injustice in layers of democratic systems, and stated willingness to make attempts to rectify those injustices both within and external to the person's immediate sphere.
5. Determination of clear delegation of authority by residents/program participants or their Guardians, if they need to be represented, in order to honor their dignity.
6. Importance of accessibility for all members of the community to communal spaces, meetings and decision-making bodies (Young 2000, 6,9,12).

I asked participants in the study questions about their perceived role in the community, how they saw themselves change, if at all, as a result of residing in the cohousing community and/or participating in New Growth's support programs, and how they understood the relationship between various entities in the neighborhood and the FBO in developing opportunities for increased inclusivity for individuals with disabilities. The interviews I conducted each lasted between 45 and 90 minutes, and gathered significant details concerning individuals' perceptions of their experiences. I asked each person to select a site for their interviews at which they could be comfortable. For some this location was the New Growth Ministry center while for others it was their

home or porch or a local business. As matters evolved, individual choices regarding interview location played a key role in my observations of their comfort, not just with the questions, but with their larger environment as well. I found that the choice to be interviewed on a porch for one interviewee, for instance, suggested a feeling of rapport and general enjoyment in sharing their thoughts. Interviewee selected locations also provided unplanned opportunities for interactions and conversations with other residents in the community, and allowed me to witness some of the informal interactions that participants and staff highlighted as being vital to agential possibility.

I transcribed each interview as soon after each conversation as possible. I then coded each with an eye to Young's criteria concerning participatory possibility. I recorded statements my interviewees employed that Young argued pertained to democratic agency including dignity, identity, acceptance, authority, participation, ownership, and accessibility. These concepts constituted my initial constructed codes.

I first transcribed each interview using the online software Otranscribe. Then, I conducted a careful reading of the interviews paying careful attention to statements that seemed to reflect the elements of Young's framework listed above. In this process, I noted that there were considerable mentions related to these components that also referenced the importance of faith and belonging to the character of community.

After this first reading of the interviews, I began to comb the transcriptions and highlight specific excerpts regarding the individual's experience with the organizational partnership and their feelings of personal agency. I color coded those statements based on the six criteria that Young identified as necessary for the exercise of democratic agency. I then began the process of assigning codes related to these excerpts that reflected the

implicit and explicit meanings of the accounts, and how those reflected their own understanding of democratic agency, as well as the role(s) of the organizational partnership in creating opportunities for expression.

I then aggregated these codes into a set of categories that I appeared to best approximate or fit Young's framework and participant statements. It became clear very early in this process that a theological lens was required to interpret the work of these two entities within Young's framework. While there were clear parallels between New Growth / Second Avenue and Young's approach to inclusion, study participants regularly referred to the concept of theological belonging as the foundation of all of their work. In consequence, I chose to code for words and phrases that aligned with Young's framework, but also reflected this theological framework. Those concepts included flourishing, hospitality, belonging, rhythms, faith expression, and dignity as being an inherent attribute of creation.

## **Chapter 4**

### **Analysis and Findings**

#### **Organizational Structure**

The partnered cohousing community and service center for individuals with disabilities also work with a number of other local nonprofits and churches. In their interviews with me New Growth staff members spoke about working with churches to obtain space for New Growth programs and to gain a steady source of volunteers and financial support. Because neither New Growth, nor Second Avenue adheres to a specific Christian denomination's teachings, individuals who live in the neighborhood and frequent the Ministry's programs attend a variety of churches in the area. These connections with several nearby churches, both institutionally and via its participants, have helped to expand the FBO's network, as well as its relative reach and influence.

Second Avenue itself arose from other organizational partnerships including New Growth. Partners and volunteers of the nonprofit as well as students and faculty at the local university felt that cohousing community would help to fill a basic service gap for persons with disabilities, and provide a unique, communal living experience for individuals with and without disabilities. As of January 2017, New Growth was also the owner and operator of the Edges House, a group living arrangement among long-term volunteers and Ministry participants with disabilities who have chosen to live together. They share meals, chores, and everyday life while also participating in, and supporting the mission and work of, New Growth Ministries. Each individual in the house has their own bedroom and a cabinet with a lock where they can choose to keep valuable or private items. The residence is not meant merely to be a place for living, however. The Edges



House arose from New Growth's mission to promote meaningful relationships between people with and without disabilities. In order to foster such ties, Cormick, a House resident and a pivotal figure in its creation and development, described the use of spaces such as the chapel (which is accessible by a sliding glass door situated at the back of the home, 'facing' the interior of the neighborhood), and the Christ Room, which allows passersby, visitors and those in need to experience what residents describe as Christian Hospitality.

Their definition of this concept draws on Catholic theologian Peter Maurin, whose "Easy Essays" provide a framework for communal life that values each individual as vital to the collective, regardless of their contribution to the larger financial economy (Maurin 1977, 2010). Maurin founded the Catholic Worker Movement with Dorothy Day in order to address the issues of urban destitution and disadvantage that plagued marginalized populations in the early-mid-20th century (and continue to do so today). For the residents and developers of the Edges House, marginalization is a present reality, and for them, Maurin's framework and influence is daily visible and relevant.

The same neighborhood is also home to the Agape House, located near its center. This facility was developed in partnership with a local divinity school. Students in that school can choose to live in the house for up to two years in cooperative and faithful living with individuals with disabilities. These students are not caretakers. Rather, their 'friends' as they are called in the framing literature on Agape House, are the main residents of the house and are capable of living largely independently, although they may require a friendly eye or caring neighbor occasionally to ensure that they are getting their needs met.

Agape House, compared to the private residences of the Second Avenue cohousing community and the Edges House, regulates its residents living styles and responsibilities more strongly. Individuals, both students and friends, are expected to engage with one another and participate in the life of the House as much as they are able. Friend residents are also expected to be able to manage things such as medications and general care taking, and must be able to sustain themselves financially. Rents for other private homes along Second Avenue largely depend on the homeowner's need to pay the mortgage, and so lease costs vary based on the individual owner and tenant situations.

Although Second Avenue, New Growth or Agape House do not explicitly suggest they are aiming to encourage socio-economic diversity in the neighborhood, the area has surely become more income diverse because of the influence of these collaborating institutions. Formally, income diversity is created within Edges House because of the expressed goal of serving individuals who were not thriving in residential settings elsewhere. Nonetheless, income diversity is also encouraged informally via homeowner relationships with persons they meet while participating in New Growth programs, or through informal interactions with visitors to the neighborhood.

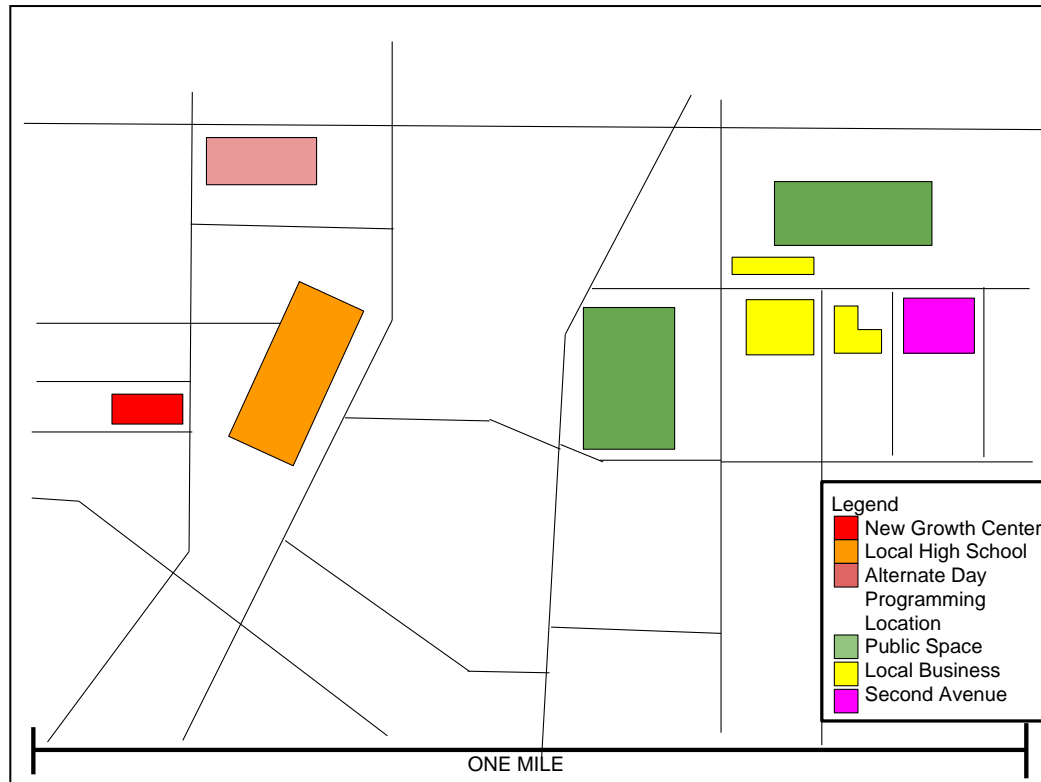
When these private homeowners establish meaningful connections with these individuals, some are even willing to create payment/rent subsidy structures that allow those with disabilities with whom they have interacted to share life with them in the neighborhood. This said, it should also be noted that New Growth does assist individuals with disabilities to undertake the steps necessary to reside in the neighborhood—residents' disabilities range from mild cases of Asperger's to those who are non-verbal. However, those residing in Agape House and those overseeing it do not distinguish

among individuals based on ability or disability. This stance allows for a diverse array of residents and participants alike.

### **Place-based Structure**

The location of New Growth and Second Avenue allows for informal spaces to be utilized for events and activities that encourage individual free expression and the development of friendships. On Mondays, for instance, daytime groups at New Growth travel to a nearby food co-op to have lunch. This activity not only provides individuals with disabilities with a chance to express preferences, but also gives them an opportunity to be seen and known by the larger community. For individuals who have largely been kept at home or in segregated support and learning environments for much of their lives, this can be an extremely positive thing, according to New Growth staff. Individuals living in the neighborhood or in the Second Avenue cohousing community also told me that they enjoy being able to walk about their environment, including walking to New Growth for activities and programming, as well as spending time at businesses in or near the neighborhood, including a coffee shop nearby, and a music hall at which New Growth volunteers who have formed a band, frequently play (Tom, Personal Interview, 2/4.2017) (Nicole, Personal Interview, 2/3/2017). A map of the larger neighborhood of which New Growth and Second Avenue are a part appears in Figure 3 below).

**Figure 3: Location of various partners around the city (The distance between Second Avenue and New Growth is just less than one mile)**



The local music hall, located just west of Second Avenue on an adjoining street, served as the venue for a birthday party for Lyth, a resident of the cohousing community and a long-time participant at New Growth, frequent performer at area churches at social events, public speaker and individual living with severe cerebral palsy. Lyth is non-verbal and unable to see, but his charismatic demeanor, wide circle of friends and impact on the community is impossible to ignore. The event, as described by both staff and residents of Second Avenue including his live-in caretaker Nicole, attracted 300 people and was covered in the events section of the city’s newspaper.

It is through occasions like Lyth’s party at locations previously ‘off limits’ to individuals with severe disabilities that Nicole says have truly given Lyth a chance to

share his unique gifts and capabilities with the larger community (Nicole, Personal Interview, 2/3/2017). Without the opportunity to engage with the population external to the New Growth / Second Avenue nexus, there is little chance for people unaffiliated with those entities to consider or to change their perspectives on individuals with disabilities. As Mark, a New Growth staff member mentioned as well in relation to Lyth's birthday party in an interview with me:

I was just realizing that tons of friends with developmental disabilities were just hanging out in [the music hall]. And they were just there, and it wasn't like we brought them, they were just there because they wanted to be. And I'm so used to it but then I stopped and thought like wait. This is extraordinary. And it shouldn't be extraordinary but it is. Like if you were a random person coming into that space that night, you'd be like what is going on? (Mark, Personal Interview, 2/2/2017)

Relationships formed at New Growth and Second Avenue appear to create the conditions that permit events such as Lyth's party to take place. However, the staff and leaders of both organizations recognize that merely working within the communities they have cultivated will not shift the dominant paradigm of society that still frequently "others" and ignores individuals with disabilities. In her interview Margot, the executive director and co-founder of New Growth, underscored the importance of having individuals from New Growth go out into the community and be seen participating in informal activities, such as parties, walks and general 'hangouts' and large, formal events. One such occasion is the New Growth Talent Show that draws upwards of 2000 people each year, many of whom are completely unaffiliated with either New Growth or Second Avenue (Margot, Personal interview, 2/21/2017). Margot also described the importance of creating opportunities for individuals outside the community to "dip their toes in the water" before participating in an event with New Growth program

participants, such as Tuesday Night Live, which features a meal with social time, songs and games and a brief scriptural message. New Growth aims through these events to create spaces that allow individuals with disabilities to be the stars, in a sense. They are the performers, the directors and largely the ones reaching out to other people in their church and family circles and inviting them to step into these places – both physical and relational— in their lives. It is through these events that Margot also believes individuals who may not have ever encountered or spent time with a person with a disability may realize how little difference actually exists between people, and how easy it can be to establish relationships between people of all abilities (Margot, Personal interview, 2/21/2017). However, there is also the recognition that safe, comfortable, physical spaces are needed for this to occur (Margot, Personal Interview, 2/21/2017) (Carly, Personal Interview, 2/3/2017).

In order for individuals to be comfortable in these environments, they need to experience a sense of stability and ownership over the physical spaces they must inhabit and traverse. New Growth has worked throughout its ten-year life to create comfortable, welcoming places that are large enough to accommodate the visitors that arrive on Tuesday nights and small enough to allow for one-on-one dialogue. The staff of New Growth mentioned the importance of individuals feeling a sense of ownership and belonging to and perceiving themselves as supreme over the physical space, because when they begin to see that location as a second ‘home,’ so to speak, they become more comfortable inviting other people into it. The New Growth staff members deliberately sought to create this sort of welcoming environment because they had recognized the importance of spatial stability and feelings of safety and welcome when that ministry had

first begun its work with at-risk youth.

Although this orientation has created spatial constraints and forced New Growth to utilize a nearby church in order to accommodate everyone for its daytime services, they also allow individuals with a disability to be able to provide hospitality to someone else. Stability and ownership of physical place, whether that be the New Growth Center, those with disabilities to initiate and take ownership of relationships. They are the ones inviting people in and providing a service, rather than just passively receiving support or attention from a paid person or family member. Having space to take initiative and leadership concerning friendships provides individuals with disabilities an important sense of agency. In such cases, ideally, they do not perceive those visiting them as ‘assigned’ to them or acting out of pity. Rather, they are mutually choosing to invest in one another’s lives and the spaces help to create that possibility.

At Second Avenue, the importance of mutuality in physical spaces becomes clearer on a day-to-day basis. Individuals share resources, knowledge and time, and are reportedly quick to help a neighbor with a request or problem, and actively share their life updates with the group. This occurs in this neighborhood because individuals live in an environment that is structured around ideals of relational community; a model that aligns with the aims of cohousing, irrespective of whether its residents include individuals with disabilities.

Second Avenue also provides a place for individuals both with and without disabilities to express themselves and participate in community life in ways with which they feel comfortable. For people with disabilities with whom I spoke, life in the cohousing development represented a significant departure from the rigidly planned

schedules that many had experienced in group living arrangements, facilities or at home prior to living in the neighborhood. They were able to structure their interests and goals largely autonomously with the support of their friends and neighbors when needed. Second Avenue provides fairly wide spatial freedom for persons to live in a variety of situations (alone, with one roommate, with a number of roommates, etc.) and with little oversight. They are also provided with spaces that allow them to host and welcome others or that give them the opportunity to retreat from other people when they believe they need a break. There is not always someone directing these individuals as they go about their lives, and they are free to refrain from activities as they wish. This is not to say that they live in a state of isolation. Individuals in the cohousing community with and without disabilities informed me in interviews that although they have an independent life, they feel supported and cared for by their neighbors (Victoria, Personal Interview, 2/11/2017) (Samantha, Personal Interview, 2/10/2017). Because of this, they give up some degree of autonomy to live in an environment of actively invested neighbors.

### **Young's Framework as Evidenced by New Growth and Second Avenue's Values**

Second Avenue and New Growth have created spaces and opportunities for people with disabilities to exhibit personal agency and democratic inclusivity per Young's criteria when her central concepts are compared to the theological discourse cohousing community residents and New Growth staff and participants employ. Words in bold below indicate the categories that I parsed from my analysis of the interview data as the participants described their experiences with personal agency, and how those experiences related with Young's framework. I undertake that translation or comparison



next:

1. A willingness to question dominant frameworks, to engage with new ideas, and change established rules and expectations for a common good occurred through the partners' shared definition of **Hospitality**.
2. A recognition of and support for a multitude of experiences, voices and methods of communication was exhibited through the two entities' conception of **Expressions of Faith and Self**.
3. The importance of group affiliations and identities and an acceptance and allowance for multiple individual ties with different groups was exhibited in the two organization's members' shared understanding of **Identity and Belonging in the Kingdom of God**.
4. The partners recognized institutionalized injustice in the larger society and voiced their desire to rectify it by suggesting they encouraged participants to **Flourish**, both as individuals and within relevant groups.
5. The two organizations recognized each person's right to have authority over himself or herself and the chance to make decisions individually and to participate in decision-making for the community in which they reside in how staff and residents viewed **Authority as Stemming from the Ultimate Authority of God**.
6. The two organizations' focus on making physical and organizational spaces accessible was evidenced in how each viewed the importance of **Formal and Informal Spaces** and opportunities for individuals to express agency within them.

### **Hospitality and Changing Norms and Expectations for the Common Good**

Both Second Avenue and New Growth staff members embraced a common idea

of hospitality. Each also embraced the ability of all members of the community to demonstrate it to one another and their friends and relations beyond the confines of the two entities. For individuals without disabilities, this was primarily evidenced in how they viewed privacy, social needs, vulnerability and mutuality. Volunteers often entered the New Growth space thinking they were giving something to help someone with a disability, but the FBO's staff hoped instead that they would:

come here and experience this really beautiful way of being that they might not have experienced before and then continue on to study [disability and theology]. It changes their whole view of God. Then they devote their lives to living in communities of people with disabilities (Carly, personal interview, 2/2/2017).

The staff aims to help volunteers understand the idea of hospitality as arising from recognition of their shared humanity with people with disabilities. For Young as well as New Growth staff, “individuals are not primarily receivers of goods or carriers of properties, but actors with meanings and purposes who act with, against, or in relation to one another” (Young 1990, 29). Volunteers begin this journey toward recognition of their common humanity with New Growth residents and program participants when they are given opportunities to interact casually with people with a variety of abilities and share time and experiences with them. It is often a very humbling experience, and requires volunteers to accept a significant shift from their assumptions: many have lived their lives generally considering full autonomy and independence from other people as representing the pinnacle of the human experience. To need or rely on others would imply that they are incapable or defective in some capacity, and to be unqualified suggests that a person is not as economically productive as they could be.

Newman has described the perspective underpinning such an attitude as guided by

the difference between the economy of God and the economy of man. The latter, aims for efficiency and speed [while] Christian hospitality is content to wait, to take time, apparently to do nothing if need be. Since the aim is to be in God's abundant time of giving and receiving rather than in efficient, productive time (Newman 2007, 91).

This is to say that this concept of hospitality is not unique to New Growth and Second Avenue. Dietrich Bonhoeffer, for example, also argued that Christian relationships are vital to understanding the Christian life. He contended that individuals must, "recognize in each other the Christ who is present in the body; they receive and meet each other as one meets the Lord, in reverence, humility, and joy" (Bonhoeffer 1954, 20). New Growth volunteers must accept not only that conceptualizing individuals in light of the dominant social (instrumental) frame dehumanizes those that cannot provide for themselves or work in the market in a 'valuable' or monetized way, but that they are also vulnerable to the extent that they too cannot be financially quantified. In this view, volunteers must come to understand that full human flourishing means entering into mutual relationships with one another, and relying on those connections for support and personal growth.

Staff members argued that when volunteers adopt this view, they receive just as much or more than they are 'giving' to the individuals with disabilities. In consequence, the New Growth staff seeks to maximize opportunities for volunteers to engage in and cement friendships with people with disabilities. Several thereafter have chosen to enter into the more informal and committed experience of rooming with individuals with disabilities.

For people with disabilities, this concept of hospitality is exhibited more through

their realizing and being given the chance to experience and enjoy mutually beneficial relationships rather than being passively served by them. Individuals with disabilities are encouraged to accept leadership roles within New Growth and to share their views and interests with the other participants and staff. Leadership, according to Michelle, a staff person at New Growth, is “the opposite of top down—it’s hearing people and knowing people and responding to that” (Michelle, Personal Interview, 2/2/2017). Individuals with disabilities are not generally given the chance to enter into these types of experiences and spaces—for the most part, they have believed and been told that their opinions were either invalid, or that their ideas or desires are inefficient or more difficult to implement than people are willing to countenance (Swinton 2011). New Growth, however, aims to reverse this thinking by placing participants’ thoughts in a place of primacy over traditional organizational strategies. The stated aspiration is that those with disabilities are not only welcomed into the community, but also its true drivers.

The types of skills that individuals learn through these formal avenues at New Growth are encouraged in the more informal atmosphere of Second Avenue. In that space they are able to deepen relationships that began through formal participation in activities at New Growth, and to open their more private world, as and when they are comfortable in doing so, to a wider range of individuals. It is through opportunities to be the host in relationships, rather than recipients of hospitality that residents say they begin to feel ‘known.’ Nicole stated, for example, that at their previous residence, she and Lyth were unable to open their doors to other people because of a lack of space, and Nicole’s own fears of being judged for not having a home that was always neat and orderly. However, she also remarked that on entering the Second Avenue community she noticed how no

one seemed to have an explicit standard of what a home or lifestyle should look like—all were welcomed regardless of how they chose to portray themselves. That fact gave her confidence to open her home more broadly (Nicole, Personal Interview, 2/2/2017).

Tom, a resident of the New Avenue cohousing community since 2012, described for me how the mentality and strategy encouraged at New Growth of “living into your identity,” rather than accepting the view of who you are assigned to you by society had allowed him to rethink his role in the community, and be more willing to be more open to his neighbors, rather than remain shut away. As a person with Asperger’s, Tom suggested that his personality put him at a disadvantage socially. Although he described himself as “kind of a loner, I’ve found a balance ... I think I’ve tried to live as sacrificially as I can and I was very authentic” (Tom, personal interview, 2/3/2017).

This ethos of openness constitutes a significant shift from the dominant narrative of welcoming and hospitality in our culture that implies adherence to a set of norms and standards related to when and how one should accept visitors, as well as who should be given hospitality (Newman 2007). Hospitality for Nicole and Lyth is more about creating an atmosphere of welcome that encourages mutual, loving friendships than it is seeking to impress others or attempting to portray themselves in a certain way. They told me that they now can be hospitable and welcome their neighbors with and without disabilities into their home because they feel a sense of ownership and agency over their space and their relationships (Nicole, Personal Interview, 2/2/2017).

In the Edges House, hospitality is not only part of the social structure of the dwelling, (individuals are encouraged to share the space with nonresidents and friends from outside the community), but also includes areas specifically set aside for welcoming

strangers, including the Christ Room. This space, as described by Cormick, is intended to be a place of rest and belonging for people who otherwise do not daily experience the supportive, mutual, relational lifestyle that Edges provides (Cormick, Personal Interview, 2/3/2017). This includes caretakers for friends at New Growth in need of respite, other participants living in less than ideal situations and people completely unaffiliated with the organizations, including, potentially, refugees.

Indeed, the development of the Edges House required Nicole to shift her thinking concerning what a supportive living environment could look like and how it could be financed. In her interview, she described her discussions with Cormick before the development of the house, stating that she would:

...Like to thank you for not listening to me. I've been doing this for a very long time and you all have showed me a completely different way of doing things that would not have even occurred to me ... we're pushing the limits of creativity of how you can use services (Nicole, Personal Interview, 2/2/2017).

Hospitality and welcome in this sense require a modicum of creativity and a willingness to learn from your neighbors; a desire to let their thoughts enter your thoughts, as you would welcome them into your home. It requires a change in expectations, which Young has also described as vital to democratic agency (Young 2000, 34).

This orientation is also played out in the weekly house meetings at the Edges House, during which all residents—with and without disabilities—discuss how things are going, what needs attention, and to allocate responsibilities for the week. Cormick described to me how this experience has been one in which he had come to recognize the difficulty and yet the necessity of “listening to consensus and not trying to force consensus” (Cormick, Personal Interview, 2/3/2017). Both New Growth and Second

Avenue seek to encourage actively listening to the desires of residents and participants, and responding to them as best as one can. However, in order to achieve this level of respect and dedication to persons individually, rather than merely achieving a stated benchmark of success, one must pay significant time and attention to developing relationships that allow people who may have difficulties communicating their needs clearly or who may not have had the experience of being treated as important to a decision-making body or had their voices heard. These communities working in tandem not only seek to create such opportunities for people with disabilities to express their personal agency, but also to encourage relationships between volunteers, staff and participants, that allow them to be understood fully, and taken as seriously as individuals without disabilities.

One of the ways that people in these communities deepen the friendships that create mutuality is through celebrations of events, both positive and negative. At New Growth each week at Tuesday Night Live, both volunteers and participants are called forward and celebrated if their birthday falls within the week. Each individual is singled out and praised and reminded of his or her importance to the community. All interviewees noted the importance of celebrating milestones and life events with the community, as these provide other members opportunities to step into an informal space in which the person being feted is simply a friend. The story of Steve, as told by Mark, a staff person at New Growth, highlights this idea well:

Steve is an individual living with Down Syndrome, and in 2014 he began walking for enjoyment and exercise around his neighborhood. With the help of a pedometer, he began tracking his steps, quickly realizing that his own expectations and the expectations of his friends and family were much lower than he was capable of. He set a goal of five million steps, and on the day of his five millionth step, he was greeted with a banner held by dozens of his friends from

New Growth at Second Avenue. Because the goal was important to Steve, it was important to his friends and community at New Growth, and it wasn't random, it was the outworking of a particular circumstance of these relationships of knowing and being known (Mark, Personal Interview, 2/2/2017).

What makes New Growth and Second Avenue different from traditional service providers is the idea of relationships existing out of love, rather than as payment for services – which for people with disabilities, is usually extremely different from their past extra-family experiences.

The same approach to welcome and care occurs for neighbors in times of trial as well as success. When Rob, a long-time resident and volunteer at New Growth, heard that his son had passed away in a car accident in 2014, the community was quick to jump in, helping to drive members of the family all over the state to pick up children at the coast and in a large regional airport in the middle of the night. They provided a space for collective grief among the community to be expressed, and showered Rob's immediate family with love and support that is atypical in less interdependent communities. Aid arose not simply from other parents, but also from individuals in the community with disabilities and their families. On the first anniversary of his son's death, Rob recalled how he and his family were called to their yard outside, where Second Avenue residents had gathered to sing hymns and host a candlelight vigil. Because of the deep relationships forged through living in the Second Avenue neighborhood, Rob's personal tragedy was shared and known by his neighbors who were quick to put aside their own schedules to help their friend in need (Rob, Personal Interview, 2/4/2017).

New Growth may provide the formal opportunities for relationships to begin and grow, but it is through getting to know a person well enough to want to share in their life experience in informal contexts that the sort of welcome and love required by a doctrine



of hospitality becomes evident (Newman 2007). As Margot stated when describing the relationship between the two:

I would say they're just different expressions of the same way of living that understands and is growing and it looks really neat and our friends are our teachers (Margot, Personal Interview, 2/21/2017).

Such a framework supports Young's criteria for democratic agency and it also requires a rethinking of American society's dominant paradigm for community: in our neo-liberal society, we do not want to share our spaces, belongings, or struggles with other people (Young 1990). Vulnerability and reliance are seen as a weakness rather than strength, and there is a distinct focus on doing what is best for yourself and your immediate circle. These communities widen that circumscribed circle by adhering to a doctrine of hospitality that says that how you define yourself, your lifestyle and the people around you should be shaped and changed constantly by your environment and the people with whom you share it. By communicating the real and often messy parts of life with others, individuals learn, "about the weaknesses that characterize[s] both sides of such relationships, our illusions are stripped away, and we begin to understand the reality of God's grace" (Brock 2012, 18). Such an understanding of learning and growth through reversing the roles of serving and being served allows individuals with disabilities to step into spaces they previously were unable to occupy, and express personal agency. Further, individuals without disabilities are given the chance to recognize for themselves their own vulnerabilities and need for relationship, and enter into ties with a respect and encouragement for their friends that allows them to express themselves freely. These attitudes were evident among all of those I interviewed for this study.

## **Diversity of Expressions of Faith and Self and Young's need for Diversity**

Relationships allow individuals to express themselves more comfortably, but relational communities according to the staff and residents of New Growth and Second Avenue also acknowledge the importance of listening to individuals of all ability levels, recognizing a multitude of experiences and voices, and welcoming different ways of sharing as valid and vital to their functioning (Cormick, Personal Interview, 2/4/2017) (Mark, Personal Interview, 2/3/2017) . Diversity is a necessary part of democracy, according to Young, because it,

fosters the development of capacities for thinking about one's own needs in relation to the needs of others...[and] tends to promote just outcomes, then, because it is most likely to introduce standards of justice into decision-making processes and because it maximizes the social knowledge and perspectives that contribute to reasoning about policy (Young 1990, 92-93).

For individuals with disabilities, New Growth or Second Avenue may be the first time that their uniqueness has been seen as a gift rather than a burden, according to staff members and participants (Carly, Personal Interview, 2/3/2017) (Michelle, Personal Interview, 2/3/2017). This difference in understanding arises from a, “conception of justice which challenges institutionalized domination and oppression [which] should offer a vision of a heterogeneous public that acknowledges and affirms group difference” (Young 1990, 10). Through both formal and informal activities and opportunities at Second Avenue and New Growth, individuals with disabilities are given the chance to live into their ‘true self,’ and come to believe that who they are is important to their friends, their community and ultimately to God.

Young argued that many participants and residents with disabilities have

experienced frustration and alienation from various groups because those individuals in authority or simply other persons without disabilities have demanded that they must adhere to a set of expectations or standards in order to participate—including in religious communities (Young 1990, 60). Young has contended that these expectations stem from an “articulateness privileged” position (Young 2000, 48). Participants and volunteers alike stated in interviews that they felt a unique sense of freedom at New Growth and Second Avenue to express themselves (Victoria, Personal Interview, 2/11/2017) (Carly, Personal Interview, 2/3/2017). Staff at New Growth have encouraged residents and program participants to discover their true selves through relationships, “Volunteers and participants alike, [the message is] I am celebrated for who I am and what I’m bringing into this place...[and] empowering people to serve one another and celebrate each other” (Carly, Personal Interview, 2/2/2017).

Program staff at New Growth whom I interviewed argued that one of the ways to encourage authentic expression is by appealing to, and allowing people, to exercise their faith in unique ways (Mark, Personal Interview, 2/3/2017). There is no official, formal or national theological doctrine to which either New Growth or Second Avenue adheres; they are unaffiliated with any particular church, so individuals are free to express their faith in whatever way they believe God may be leading them. The recognition of diverse faith experiences and what they contribute to a larger, communal faith story is what draws people to New Growth, according to Carly:

The really beautiful thing is that we have a lot of people who may or may not be able to articulate that truth or even really conceptualize it in their brain...and so I think another reason people are drawn to New Growth is because you start to grasp that when you’re here, like “oh my gosh, if this person is loved by God and forgiven and lives into this grace, then it can be true for everyone (Carly, Personal Interview, 2/2/2017).

A truly equal respect for a diversity of faith experiences comes with recognizing that each person's unique experience is necessary to understanding the whole. Engaging with individuals with disabilities living their faith in their own way encourages participants and volunteers to search for their true selves as well, which creates mutual supportive relationships between people with and without disabilities. Lavender, a resident and volunteer at New Growth, for example, found that through interacting with a number of different personality types evidenced by individuals with varying disabilities, she discovered some hard truths about herself and her own willingness to live sacrificially and respectfully in the community:

We're missing out on the fullness of ourselves when we're not living closely with other people. And people who are different. Like (laughs) wow there are so many different people living in this neighborhood. So many different personality types, so many different like hobbies and ... interests and yeah. It's hard like you learn a lot about yourself and it sucks sometimes (laughs) like I realize that I am not a very nice and giving person and that is spotlighted with community (Lavender, Personal Interview, 2/10/2017).

It is through such experiences in the communities I studied that individuals without disabilities begin to recognize how the dominant framework of neo-liberalism and capitalistic worth leaves out individuals who are incapable of adhering to its set of established norms or standards for what constitutes a good or productive life. They begin to recognize that people experience life in diverse ways, and each is valuable for its own sake.

This acknowledgement and understanding was also articulated in my interviews by individuals describing their experiences of choosing to live in Christian faith independent of their parents or guardian. For Tom, Samantha and Victoria, realizing that they did not have to fit a prescribed mold or adhere to a set of norms in a specific church

setting was liberating, and set them on a course of further agential expression:

I was in the faith that I just ... I didn't feel trapped, I felt like you predominantly have to be this way and you can't separate yourself, so I was like, ... I was like, if I move to Second Avenue I have to start all over. And I did and I felt better and now I'm like, in a community where people can know me and I can just ... whoever, but just go somewhere and learn about God in a way that's not like ... you have to do this by the book. Like, you can just go as you please and do what the faith believes you should do and come as you are in that. And be accepted (Samantha, Personal Interview, 2/10/2017).

Tom, whose parents were only marginally involved in churches in his hometown, had chosen a nontraditional lifestyle. When he recognized that partying and going to clubs was unfulfilling, he chose to accept a message he heard from a televangelist regarding salvation, and devote his life to Christ and Christian living. Tom shared in his interview that this change not only prepared him for living with others, but to live in a sacrificial experience of community, such as Second Avenue. Tom told me that his faith is personal; that he chooses how and where to worship and what he personally believes about various doctrines, but he also recognizes the diversity of experiences that brings people to the common experience of being loved by Jesus. He sees his own trajectory as being largely different from the other members of the community who may have grown up in a more traditional Christian home, and he recognizes and appreciates how those individuals both encourage and support other's diverse faith experiences, including his own:

I try to see everybody fairly. I really was very insidious about it. I thought it was hard to be emotional to people, so I treat people just the same you know, I've had some ... I haven't had the greatest relationship with my parents; it's just like ... some of my intention is to try to walk through that with Christianity, and ... it's kind of shaped me because I cared a lot of hatefulness and low expectations and not really expecting much and now I'm doing well for myself. I battled with low expectations, I battled with social rejection ... I've had to have lots of grace with people (Tom, Personal Interview, 2/3/2017).

Samantha, an individual with a disability, has been a resident of Second Avenue for almost a year and a participant at New Growth since 2013. She has found that her greater independence in her living situation has allowed her to develop a deeper faith than that she had developed going to church with her parents, but feeling trapped by a formulaic, traditionalist approach to Christian community. Samantha chose to leave her mother's home when an opening became available in a shared apartment with former New Growth fellow, Lavender. In this context, Samantha was given the chance to explore various churches and alternate forms of faith expression.

For Tom and Samantha, faith provided an entrée to independence. It is clear that for some residents with disabilities living in the Second Avenue development, this was the first time they had been able to express a fundamental part of themselves. They had previously either adopted the views and faith tradition of their parents or caretakers, or had not been expected or allowed to participate in religious life at all. For her part, Victoria was able to go to church occasionally with her Grandmother, but was often kept away from communities of faith by her mother, who did not believe that she was capable of accomplishing or participating in a variety of independent and everyday tasks. Coming to this community allowed her to see that she did not need to be limited by what made her different:

Even though I have a disability, this community did not tell me I couldn't be this or couldn't be that because of my disability (Victoria, Personal Interview, 2/11/2017).

By having the chance to choose and explore her faith identity, Victoria found that many of her mother's perceptions of her capabilities were wrong. Contrary to what her mother had long suggested, she found that she was capable of living independently and of

developing a lifestyle quite different from that her mother had expected of her. For example, while her mother was leery of the mixed racial composition of the community, Victoria now disagreed:

As long as they care about you and they love you and they're here to protect you, ... that's all that matters. I'm not going to turn my back on someone because of the color of their skin (Victoria, Personal Interview, 2/11/2017).

Agape House, according to Carl, its director, aligns itself with the same type of flexible theology that New Growth has embraced, so that even though individuals with disabilities live side-by-side with master's and doctoral degree students in a specific Theological Studies program, the staff seeks to encourage all to understand that all people enjoy the unqualified love and acceptance of God.

Carl also sought to realize mirror images of this relationship in ties between people with and without disabilities through a "posture of acceptance" in which people recognize that they "are ultimately led by our friends with disabilities ... and just to experience acceptance from our friends with disabilities ... that comes with just being present and doesn't require anything else" (Margot, Personal Interview, 2/21/2017).

However, this posture of acceptance does not necessarily translate to a wider audience, where individuals with disabilities may find that they continue to be ostracized by people and institutions that do not recognize their gifts as valuable. For Margot, respect comes from interaction and relationship between people with and without disabilities, which she believes drives the initiatives that both bring people into New Growth, and send people out into the broader community equipped with new-found self-awareness and confidence.

This respect translates into formal decision-making opportunities in which

individuals with disabilities serve as primary leaders of initiatives. These include not only leadership opportunities, but also chances to express themselves within group activities in ways with which they feel comfortable, such as through song and dance, sharing artwork and asking questions. Allowing individuals with disabilities to choose the activities in which they choose to participate and how they want to become involved based on their own personal interests, is another way in which New Growth aims to provide its clients a diverse array of experiences. In many cases, these activities are geared toward acquiring a skill that attendees can use in the larger community including, for instance, learning to utilize public transportation.

Such experiences have proved enlightening, not only for the participants and staff, but also visitors to New Growth events. One such activity is ‘wondering’ sessions, which are Biblically driven lessons during which participants read scripture and act out the scene and ask whatever questions intrigue them regarding the reading or its interpretation. In one such session, Lyth and a group of his friends ended up being paired with a leading theologian from the nearby university, an individual who has been described as the most important religious thinker of our time. The professor and the group of friends were tasked with acting out the story of the Woman at the Well from the Gospel of Luke.

Mark described this event to me and suggested that in a more traditional setting everyone in the group would likely defer to the theologian for guidance in interpreting the scripture. However, he indicated, this was not so in this case. Instead, Lyth and his friends held everyone’s attention. Later, in the questioning part of the session, Tom noted that the professor observed positively that his voice and interpretation were valued as



those of any other person in attendance, whether verbal or non-verbal, and whether able to express their views orally or via less traditional means.

For Mark, the experience demonstrated how these activities truly created equal appreciation for a diversity of expression. Here was one of the world's foremost theologians being treated like another guy on the same plane (perhaps even on a lower plane, due to Lyth's popularity in the community), as people with developmental disabilities. Conversely, individuals who had been severely marginalized and treated as worthless for much of their lives, were allowed to express themselves and share their thoughts in an equal setting with a scholar with whom many students would be very intimidated to share a theological conversation. To Mark and the rest of the group,

[the professor] was just another guy, it was just a different space than he's used to and it was kind of, again, about reversing the roles a little bit (Mark, Personal Interview, 2/2/2017).

Margot offered a related notion in her interview with me. She suggested that the idea that people need to mold themselves to a certain accepted standard of presentation, communication or expression diminishes the richness that comprises diverse communities. In describing how she sees the relationships between people with and without disabilities displaying themselves rather naturally, she observed:

I think it's something about how we're not diminished by molding ourselves to be more a vision of what we share in common than what divides us. But it's easy for us to diminish others if we're coming towards them from an 'on high' and above way" (Margot, Personal Interview, 2/21/2017).

It is these friendships and the ways that they cross what are typically considered normal barriers to relationship that represent the foundation for New Growth's approach to encouraging agency among people with disabilities through diverse forms of

expression. When people are able to move from a formal experience with a person with a disability to a more informal environment of living together and experiencing the day-to-day with one another, they realize that they are not so distinct that they cannot enjoy a meaningful friendship. It is through these diverse interactions as well, that the staff hopes that volunteers and participants will begin to see God in one another. In their interviews, they suggested to me that they hoped that through relating to another person whose entire worldview had been shaped very differently than their own, participants and volunteers would come to recognize the depth of Christ's love for all. Once that realization has occurred, individuals can begin to celebrate and encourage one another's autonomy and free expression. Through such friendships, for example, Nicole argued that:

There's a certain type of person that connects with Lyth. And I think this neighborhood has a very high proportion of those types of people that are able to connect with Lyth . . . and when that happens, then he shows more of himself and then that draws more people in and that's how people grow and learn. He knows he's with people who know what he's capable of doing and that matches how he sees himself (Nicole, Personal Interview 2/2/2017).

Whereas outside the community and in his previous living environments, Lyth had often been ignored or considered incapable of understanding other people or having relationships, other members of these communities now described him to me as the "coolest guy around". He also enjoyed a wide circle of friends and a steady girlfriend. These relationships and the encouragement they provide have allowed him to express himself in ways not typically offered to persons with profound disabilities. As Newman has suggested more generally, there is a "radical openness to the other, attending to him or her in sharing and receiving insights and perspectives about self and world" (Newman 2007, 125) that is very unique to this community.

Lyth is a regular musical artist at worship services around the community, the

recurring final act of the New Growth Talent show, and was described as a close friend by a number of individuals at New Growth and Second Avenue in their interviews with me (Cormick, Personal Interview, 2/4/2017) (Victoria, Personal Interview, 2/11/2017) (Mark, Personal Interview, 2/3/2017) (Tom, Personal Interview, 2/4/2017). The environment that New Growth aims to create, which allows individuals to come into contact with a diverse pool of people can then be deepened through meaningful, everyday interactions. These contacts with volunteers and other program participants can provide an encouraging environment for the cultivation of independence and personal agency. These relationships also create opportunities for continued personal growth, as well.

### **Identity and Belonging to the Kingdom of God and the Importance of Personal Choice and Group Association**

In order to accommodate this variety of life experiences, expressions and interests, a variety of personal affiliations must also be allowed according to Young's framework (Young 2000). At New Growth and Second Avenue, this criterion plays out through a shared understanding of belonging; that people belong to God, and to one another, and those individuals may freely choose whether to develop or deepen relationships of belonging. Belonging to one another and to an even vaguely defined group affiliation also helps participants identify a shared good or goal around a certain theme and encourages group collaboration in support of it (Young 1990). This sense of belonging not only empowers individuals who have long felt ostracized by society to believing that their contributions are valid, but it also encourages them to take personal ownership of their relationships and of causes that are important to them (Young 1990).

Such an understanding of identity presupposes that everyone possesses equal and inherent dignity because they are created by God. In consequence, they are entitled to a life experience that values them and allows them to express agency over themselves and their communities. New Growth staff repeatedly expressed this perspective to me in my interviews with them. This comment offered by Carly exemplified this orientation:

You're accepted no matter what you're bringing to the table. So, to me, that's not a niche. That's what it means to be human, what it means to be yourself and be accepted for that (Carly, Personal Interview, 2/2/2017)

Mark put the same issue this way: "God is someone who has claimed the whole world for himself" (Mark, Personal interview, 2/2/2017). In this view, humanity includes all people regardless of whether they have chosen Him. This view suggests that not only do all people belong to God, but all individuals are important to God regardless of their abilities. For Margot, all people already belong to God through his claim on them through Jesus, and this has important consequences:

One-way of looking at the Kingdom of God is to say believe and then you can belong, ... but what we're saying is belong therefore believe. Everyone belongs to God by creation and redemption; ... belonging is something that everyone shares in common. We all belong to God and to one another whether we know it or not. (Margot, Personal Interview, 2/21/2017)

This orientation implies that New Growth would not deny individuals access to their programs on the basis of a set of a priori criteria. Instead, in this view, all must be welcomed and dignified as members of the Kingdom of God:

You belong. Jesus is for you, we are for you and we want to walk with you in your life and be friends with you and learn from and with you. You are a part of our community and our family. You don't have to have this SSI or this funding or whatever like we want you here—*you already belong here and you haven't even come*. You don't have to fall into really particular categories to come in the first place (Michelle, Personal Interview, 2/2/2017).

This commonly held view and identity is something that becomes most apparent when individuals leave these communities. Nicole described how a recent trip to a rural church to visit a former Agape House resident reminded her of just how unaccepting the outside world could be. When individuals stared at Lyth, or spoke to Nicole about him as if he was not there, she realized just how much of their identity and feelings of belonging had stemmed from living in Second Avenue and participating at New Growth:

We don't see that... We don't feel that... Because no one here feels that way about him. They understand him... It really does make a difference when people understand you and understand how you live. It takes a whole lot of time out of a relationship when people aren't asking 'how does that computer work'—when people just accept that's how Lyth talks. That's just how we live (Nicole, Personal Interview, 2/2/2017).

This recognition of inherent dignity is what drives the theology of the Second Avenue community, the other formal houses in the neighborhood and New Growth programming as well. Rob argued that a diversity of faith experiences and expressions of self were what united individuals and that through relationships with others, patronizing actions such as those Lyth had experienced during his recent trip could be largely avoided. This stance actually occasioned the split between what became New Growth and the national Christian youth organization it succeeded. If people considering or questioning a life of faith believed that at some basic level they were the same as all others (meaning, they experience the same salvation and the same means of grace as people who cannot conceptualize their own sin), then they would see that there is an affiliation under the love of Christ that makes everyone's life experience important for the flourishing of the collective. Carl, described how this stance manifests itself at the Agape House:

Jesus calls people to himself, he loves everyone and when people come to Jesus, they find that they get all of Jesus which is his body, the church, in whatever form that takes shape is as simple as whenever one or two or three are gathered, there is Jesus. We find ourselves embedded in this community of believers (Carl, Personal Interview, 2/14/2017).

This universal acceptance creates an organizational and social politics of hospitality, because “it generates a notion of the good as well as the true and the beautiful known through communion, koinonia, and friendship” (Newman 2007, 142). This common understanding that everyone belongs to the community by virtue of belonging to Jesus— without the requirement of a specified church or religious doctrine to which participants must adhere— was difficult for Lavender to accept:

The only reason that it has grown so well without the foundation of the church is because New Growth has been such a strong place of faith, and there’s just a strong understanding of what it looks like to live in faith (Lavender, Personal Interview, 2/10/2017).

New Growth then, though it is ecumenical and non-exclusionary in its faith practices, works to become a place in which people perceive they have an identity and a sense of belonging. This FBO seeks to encourage individuals to understand that they innately possess dignity. This definition is not as sharply detailed as that of some other faith communities serving individuals with disabilities (such as L’Arche) because of its lack of a formal requirement for adherence to a set of theological precepts, but participants, volunteers and residents alike told me that by ‘belonging’ to New Growth, they believed they truly belong to God rather than a specific denomination, an identity that allowed them to seek to embody their affiliation and internalize its principles (Samantha, Personal Interview, 2/10/2017) (Michelle, Personal Interview, 2/3/2017) (Mark, Personal Interview, 2/3/2017) (Cormick, Personal Interview, 2/4/2017).

At the core of this recognition of identity is the importance of mutual belonging in relationships. It is not one side that gives and one that receives—individuals in the community share life experiences and struggles, and both those with disabilities and those without them routinely find that they mutually benefit from their relationships. This is what the staff at New Growth hopes to inspire through programming, but they see these relationships becoming ‘meaningful’ when they move outside of the New Growth Center.

Its focus on moving relationships outside of these programmatic constraints distinguishes New Growth as a service provider. People in this community feel loved and known by friends who care about and for them, rather than having to maintain a formal, paid, provider-and-recipient relationship. Programming at New Growth is focused not so much on providing a specific service or teaching a specific skill to individuals with disabilities, but rather on providing space and strategies for personal growth. Those operating New Growth believe that people will begin to develop a positive conception of who they are and what they have to offer the community through such relationship-building and continuous encouragement to exercise agency.

This mission is played out in everyday living experiences at the Edges House. Residents belong to one another by remaining ‘person centered’ and seeking to understand the needs and gifts of everyone in efforts to ensure a fruitful living experience for all residents. Mutuality lies at the heart of being person centered in this way:

We’re redrawing at the heart of a lot of this is just friendship. Not just friendship but friendship of great value. And it is what sort of...draws this group of people together and holds us together (Cormick, Personal Interview, 2/11/2017).

Moreover, payment for services does not completely preclude individuals from belonging to the community. Formal support people are frequent faces at New Growth,

and comprise some of the residents of Second Avenue as well. Cormick described how even though he provides respite care for Lyth a few hours a week—an activity for which he is paid—he does not believe that he is somehow ‘above’ Lyth, or that their friendship is anything but mutual. Belonging requires individuals to rethink how they understand need and support. (Cormick, Personal Interview, 2/4/2017) For her part, Samantha suggested in her interview that her experience forging friendships at New Growth allowed her to feel comfortable reaching out to them in times of need when she moved to Second Avenue (Samantha, Personal Interview, 2/10/2017). Her roommate Lavender described how this mutuality changed how she saw herself and her place in the community:

People are very quick to say like ‘I can’t do this alone I need help’... [there’s] a really clear understanding that we’re only who we are because we can depend on one another. And we’re stronger because of it. ... I need my neighbors if I am at all going to be who God has created me to be; like my flourishing self. We’re missing out on the fullness of ourselves when we’re not living closely with one another (Lavender, Personal Interview, 2/10/2017).

Meaningful relationships are also pivotal for how individuals see themselves and their own gifts. Members of the community can share what they love about another person, encourage them in a particular way or give them thoughtful advice, when sought. Such actions allow community members to create roles for themselves in the broader community while developing trust in their friends and neighbors. When prompted to describe her role in the community, Victoria suggested that other members of the community would be better at defining what that role was than she could be. Her relationships with others gave her a sense of belonging and importance, but also a feeling of security. Relationships allow for meaningful insight and advice geared toward



individual flourishing, a component of Second Avenue that functions because there is a “desire amongst all the people who choose to live there for the thriving of every other person who lives there” (Margot, Personal Interview, 2/21/2017).

This includes ownership of the identity that New Growth hopes that all participants will possess, allowing each to feel comfortable about belonging to the Kingdom of God, although even this aspiration is not a requirement for program participation.

[There’s] an ownership of your belonging . . . and some people state that and some people wouldn’t but it doesn’t make it more or less true. You’re allowed to deny that’s true and you still are accepted and belong here (Carly, Personal Interview, 2/2/2017).

This quotation suggests that the opportunity to choose or reject certain narratives about their lives resides in the individual themselves, an experience, I have emphasized above, that few people with disabilities are granted in other arenas. Young has argued that because of this societal rejection,

People have or lack self-respect because of how they define themselves and how others regard them, because of how they spend their time, because of the amount of autonomy and decision-making power they may have in their activities and so on (Young 90, 27).

At Second Avenue, residents manifest an even greater orientation to this identity of belonging through shared daily life, by dint of seeking to realize it in their community. Even when Tom felt that he was living far away from God, he knew that he desired the sort of intimacy and love that a community such as Second Avenue could provide. He said even when he had walked away from God, he still felt a sense of identity with the Church and Christ. He knew that he wanted to choose this life independently, however, without the influence of his parents. He wanted to define himself as a Child of God on his

own terms, and it was not until moving to Second Avenue that he found he was capable of choosing that life on his own (Tom, Personal Interview, 2/10/2017).

According to Young, societal definitions of perceived ability can have dramatic consequences for how individuals self-identify. The, “pulses of attraction and aversion modulate all interactions with specific consequences for the experience of the body ... dominant discourse defines them in terms of bodily characteristics, and constructs those bodies as ugly, defiled, impure, contaminated or sick” (Young 1990, 123). This freedom to choose one’s identity raises the question of how people with disabilities in the community have chosen to define themselves.

Tom described to me how, though he has an Asperger’s diagnosis, he does not typically disclose that to people or make it a central tenet for how he understands his capabilities and goals for his life. For instance, he has been working for the last few years on a book about a Christian man with Asperger’s, a volume he admits to being largely his life story. However, choosing to write a book about this element of his life has allowed him to fully accept his diagnosis and define for himself what it means to his life rather than having the narrative written for him by broader social assumptions and claims.

People without disabilities find that a desire to find belonging and purpose amongst people who love and care for you extends to them as well. Cormick began volunteering at New Growth in 2012 as he was finishing his bachelor’s degree, but began living in the community in 2013 in a privately-owned apartment when he found he desired more of what he had experienced at New Growth, and felt that he was struggling to discover his vocation:

There was still this sense as I was trying to figure out where did I want to go, who did I want to be, what did I want to do, there was this sense of like...I feel drawn

to community like I want to have a common life that I want to share (Cormick, Personal Interview, 2/3/2017).

Choosing to live in a community where he can experience acceptance has required him to reconsider how he understands success and what it means to be a young adult male in today's society. It has required, for instance, that he sacrifice impromptu nights out with friends or his ability to travel flexibly. Cormick's experience illustrates how choosing to be a part of life with other people can provide a sense of direction, purpose and stability that cannot occur without a common identity (Cormick, Personal Interview, 2/4/2017).

Notably, this shared identity extends beyond the narrow purview of New Growth and Second Avenue. For a variety of reasons, both participants and volunteers occasionally find that they have to leave the neighborhood, perhaps for only a short time, perhaps permanently. Regardless of the amount of time spent in the community or whether they are able to return frequently, if ever, to visit, people who have been a part of Second Avenue and/or New Growth find that they keep the identity and sense of belonging with people with disabilities long after they move elsewhere. One of the New Growth fellows (a group which lives in Second Avenue and works at New Growth full-time for one-year terms) confided in Victoria for instance, that although his term as a fellow was ending, he felt a call to stay involved and hopefully continue living in the community (Victoria, Personal Interview, 2/11/2017).

Lavender, a former New Growth fellow, felt the same way, and she, too, sought to maintain the rich relationships that had been cultivated through New Growth and Second Avenue by continuing to live in the intimate environment of the neighborhood. A longing

for these living experiences has prompted a number of individuals to live with friends with disabilities in houses and apartments unaffiliated with New Growth or Second Avenue, because there is no space left in those facilities proper. These experiences and relationships have allowed New Growth to remain ‘person centered’ through a period of major growth, because the network of care and friendship its staff and volunteers have nurtured has expanded to accommodate a diversity of interests and needs in diverse living environments.

The allowance for diversity in these experiences and relationships has created an environment in which people are not bound to one affiliation and do not have to give up other ties and identities to belong. They can have jobs outside of the community in any profession imaginable, can volunteer in other capacities and understand themselves as unique in their identity. For Young, “the good society does not eliminate or transcend group difference. Rather there is equality socially and culturally differentiated groups, who mutually respect one another and affirm one another in their difference” (Young 1990, 163). In just this sense, the staff at New Growth has focused on ensuring that each person is valued for their uniqueness while still perceiving that they are in a place where they unreservedly belong:

As we’ve been growing [we want] to continue that intentional care for everyone involved New Growth ... we try really hard not to be one place characterized by one type of people and one thing. We really want to reflect the Kingdom of God and that’s all types of people (Michelle, Personal Interview, 2/2/2017).

Shared identity can be a powerful driver to catalyzing individuals to rally around a common goal affecting the community, per Young’s definition (Young 2000). But it can also be liberating for a person who has been marginalized to get a chance to live in an

atmosphere of universal acceptance and question and explore how they see themselves individually within that sphere. Because the communities operate on the view that all are equal before God, that perspective ensures a sense of equality amongst group members. The mutuality that results because of this focus on equality creates experiences for people with and without disabilities to recognize and validate the life and gifts of their friends.

### **Flourishing: Recognizing Injustice in the Larger Society and Working to Rectify it Both Within and External to the Group**

In order to create conditions that encourage individuals with disabilities to flourish and experience a sense of their personal autonomy, those seeking that end must first identify the forces that have marginalized participants throughout their lives and thereafter, devise strategies and experiences to address each. Those programs and experiences cannot only aid those with disabilities, but also must serve to equip and educate those affiliated with the community to be more cognizant of injustice outside New Growth and Second Avenue.

In the broader community of Christian believers in the United States, for example, people with disabilities are largely left out of the dominant narrative; exceptionalized as ‘holy others’ or objects of charity, or completely othered by a doctrine treating them as less than capable of truly belonging to the body of Christ (Swinton 2011). In contrast, New Growth’s staff teaches the same message and understanding of the Gospels that they believe is true for themselves, that “there are not two Gospels. If it’s true for them then it’s true for me and it’s true for everyone” (Carly, Personal Interview, 2/2/2017).

The founders of New Growth recognized soon after they began their work that

there was no other relationship-based ministry for individuals with disabilities in their city, so along with a ministry for ‘at risk youth,’ New Growth staff became convinced of the need to provide services for those individuals. As the disability ministry continued to grow, the staff at New Growth saw that people with disabilities had nowhere to go during the day, and that for the most part their days were highly organized and structured so that they would learn certain skills, and were run by individuals who were paid to be there. That is, as New Growth began to focus exclusively on people with disabilities, they realized that “people living with developmental disabilities are [so] marginalized and so hidden from the rest of society” (Carly, Personal Interview, 2/2/2017), and their time is largely spent in completely separate spaces. People with disabilities are not able to cultivate meaningful friendships with people without disabilities in such places because they are treated as subordinate to their caregivers. Their relationships with other people with disabilities are largely structured so that they occur only within the prescribed context of a formal activity or class.

New Growth could provide support and relationship building within a certain span of time and in another relatively formal setting, however. Nicole described how volunteers would meet after their shifts for drinks or dinner early in the history and development of the FBO, while program participants would typically go home (Nicole, Personal Interview, 2/3/2017). At the time, New Growth was using a ‘buddy’ system through which each participant was paired with a volunteer for an evening, and according to Nicole felt very formal and hierarchical (Nicole, Personal Interview, 2/3/2017). The volunteers formed relationships under this system, but participants largely remained in a more marginalized category. Nicole suggested that New Growth’s decision to abolish the

buddy system encouraged the development of more meaningful friendships between those with and without disabilities because the power relationship implicit in the previous framework had been removed:

I think that was the barrier ... and the opportunities that they give with all of those activities just for those relationships to grow. It changes to a different one on one type of relationship. 'I'm a young person in college or just out of college and I need a roommate, I can have a friend with a disability as a roommate' (Nicole, Personal Interview, 2/2/2017).

Indeed, this change of focus and organizational structure inspired the concept of Second Avenue. Both Rob and Carl describe the concerns that were brought to each of them independently by program participants and volunteers alike. Young adults with disabilities desired greater freedom over their lives, but found that there were very few places other than group homes for them to live. Both Agape House (as a nonprofit) and Second Avenue were founded out of a mutual need: students (volunteers) at a seminary were running out of places to live and desired more of the relational experiences they enjoyed while volunteering, and wanted to see their new friends grow in their personhood and sense of agency.

Though Carl had never considered housing for people with disabilities to be an injustice in his community, interactions with volunteers and with a parent of a young adult with disabilities led to meetings with many interested parents and young adults. He began to see that affordable, safe, community-oriented housing for people with disabilities was virtually non-existent, which led to the development of the Agape House model, which is now in place in Michigan and at Second Avenue, with many more potential developments in the works. Carl described how parents and residents (both friends and students) felt that their lives had truly flourished as a result of being a part of

the community:

Once you come and spend some time with the students and the friend residents, hear their parents talk about how its transformed their lives, and you see that really with those two accountabilities, it's such a simple model that it can travel anywhere (Carl, Personal Interview, 2/14/2017).

Residents, staff and program participants told Carl that such communities are necessary everywhere (Tom, Personal Interview, 2/4/2017) (Lavender, 2/10/2017) (Carl, Personal Interview, 2/7/2017). At first, New Growth struggled with how much to get involved with these larger injustices occurring outside their immediate purview. In his interview, Mark shared how he had heard concerns from many participants about their current living situations – many of which were group homes – and the lack of interest or bandwidth on behalf of caretakers, many of whom were state appointed guardians, to help their ward get into more comfortable environments where they would be better able to flourish (Mark, Personal Interview, 2/3/2017)

This mindset was one of the primary drivers for New Growth to purchase and develop the Edges House as a place for individuals within New Growth that exhibited the greatest need for more equitable housing that would better fit their specialized needs. The staff and interested volunteer residents of the Edges House recognized that there were far more of their friends living in unsupportive living environments than they had the capacity to help (Cormick, Personal Interview, 2/4/2017). Additional volunteers who were unable to live at Second Avenue because there were no open spaces began to rethink their living situations and open their minds and homes to their friends with disabilities, a recognition of injustice that Cormick argued was significant in today's society:



I think that seeing the struggle that some of our friends live in illuminates the way that all of us struggle and suffer in different ways, and there's a lot of push in our culture...and a lot of people our age just sort of minimize or ignore or avoid that and to see comfort and security ... I think there's just these external reminders that like life is hard and fragile and so I think that something about a healthy awareness to that makes the joys of life deeper and truer (Cormick, Personal Interview. 2/3/2017).

New Growth's focus on each individual possessing full human dignity changes this marginalizing narrative without denying that those with disabilities have experienced significant injustice. Mark described the FBO's approach to inclusion through a description of God's approach to inclusivity:

God is someone who has claimed the whole world for Himself, and particularly works through those who are marginalized. Or who are treated as marginalized and says 'you are not on the margins, you belong right at the center' (Mark, Personal Interview, 2/2/2017).

The experience of marginalization for people with disabilities often leaves them with not just problems in how they see themselves, but also how they understand and relate to other people and God. They are not permitted within the environments they largely reside to develop the sort of skills and relationships that would allow them to live independently. Such environments stunt social and personal growth, which makes many people with disabilities struggle to interact with other people. This leaves them largely under the care and concern of family members or paid professionals. As Tom observed in his interview:

People with developmental disabilities are among the most marginalized because they're just popped out of high school and like 'there you go get a job, living in your parent's basement' ... you can be a high functioning person with autism and you can do everything else, but you struggle to look someone in the eye and then you ... the world just throws someone like that away. And we can't do that. We need to love our neighbor. We can't just throw our marginalized people away. It's [the Christian life] supposed to be a life of self-sacrifice (Tom, Personal

Interview, 2/3/2017).

Tom's comment suggests that those with disabilities and those without them must recognize existing injustice in order to create the sort of environments in which individuals with disabilities can flourish. With few people in places of authority in society, injustices rendered against those with disabilities cannot be addressed without the support of many in the larger society. Many of the individuals without disabilities who participate in activities at New Growth and Second Avenue do so because they recognize the injustice implicit in the marginalization of people with disabilities, and want to play a role in alleviating it (Cormick, Personal Interview, 2/4/2017) (Lavender, Personal Interview, 2/10/2017). While my interviewees told me that such is true, those who volunteer also benefit:

There's a need and by need I mean partially there's a need for folks with developmental disabilities to have a place to belong, but there's also this thirst that the world has for communities like this that we're seeing here (Mark, Personal Interview, 2/2/2017).

The relationships between people with and without disabilities play a practical role in allowing individuals with disabilities to express agency. Those without disabilities can provide vital assistance and support for individuals with disabilities such as providing rides or helping them navigate the city by foot or public transit. When these services are provided out of love for the person and the relationship, they are not seen as an inconvenience or a chore that the person must accomplish, but rather are undertaken because they want to see their friend flourish and accomplish the goals they set for themselves.

This attitude is important for both people with and without disabilities in the

community. In his interview, Tom argued that New Growth's approach to inclusion does not try to 'bring up' individuals with disabilities to a normative or standard definition of lived experience, but rather meets people and celebrates them where they are (Tom, Personal Interview, 2/4/2017). The FBO has sought to fight the marginalization of those with disabilities, as has Second Avenue, by working to ensure that individuals with disabilities are able to take on leadership roles in planning bodies and programs and activities. However, this effort has required important reflection, and for some, a major rethinking, among staff and volunteers:

Our friends with disabilities are leaders of the pack and that humility of rightfully seeing myself on an equal playing field is hugely important (Carly, Personal Interview, 2/2/2017).

New Growth works to set up opportunities for individuals with disabilities to see themselves as on an equal playing field without disabilities through activities that promote a reversal of the served–serving paradigm. People with disabilities are able to see themselves in more mutual relationships by enjoying the chance to play important roles in the functioning of the community. For example, one way that New Growth seeks to ensure this is through its New Growth Café, which charges individuals with disabilities to set up, direct, and operate a lunch café at the Center. That responsibility represents an empowering experience for persons who have not been able to direct their own projects and goals as it permits them not only to see them brought to fruition, but to share them with their friends and family and to serve them for a change (Mark, Personal Interview, 2/3/2017) (Margot, Personal Interview, 2/21/2017).

This orientation and its corollary reversal of traditional roles also occurs in the organization of community worship, a monthly Sunday church service held at New

Growth that is open to the public. Individuals with disabilities lead the musical worship, read the scriptures and deliver a message at each service. For many of the participants, leading a church service is not something they expected to be able to do because of prevailing notions of necessary capabilities to understand the meaning of the Gospel. Nonetheless, New Growth's theological framework of "belong, therefore believe" allows for this often-surprising experience for both churchgoers and New Growth participants.

Churchgoers often begin to rethink their expectations for how a church service should go, and who should be in a position to deliver the message. They also begin to rethink the experience of faith itself; by seeing an individual whom they would previously have ignored, treated with pity or shame leading them through the familiar rhythms of Christian worship, they begin to see how the Person of Jesus and His love can be evident in a diversity of situations and experiences. Staff told me in their interviews that this experience tends to leave area churches with a sense of longing for the richness of the community that including people with disabilities provides (Michelle, Personal Interview, 2/3/2017) (Mark, Personal Interview, 2/3/2017) (Margot, Personal Interview, 2/21/2017). Their leaders have expressed a growing desire to be involved in the mission of New Growth. According to one staff member I interviewed the services allow those with disabilities who offer them:

To feel like they're a part of something real and concrete where many of them are accustomed to feeling apart from everything ... if there's a person who's not conscious or able to assent to a particular doctrine, that does not mean they are barred from belonging (Margot, Personal Interview, 2/21/2017)?

The monthly services share the message of New Growth, while also bringing people into the community, which staff, residents and participants hope will contribute to

changing social attitudes toward those with disabilities. Such opportunities not only provide individuals with disabilities with chances to exercise leadership, but also allow them to, “kind of get out and be seen. It allows us to invite people who might not feel safe in other ways, in other environments to get out and explore downtown and serve and be served” (Carly, Personal Interview, 2/2/2017).

In addition to the monthly worship service, the FBO also offers New Growth Serves, in which individuals with disabilities who participate in New Growth Daytime go to a local home for the elderly and spend time with residents. This program also finds participating traveling to local businesses, such as a co-op grocery store nearby. These activities help to change the “outsiders” perspectives concerning the capabilities of persons with disabilities. These activities also keep these individuals from being ‘hidden.’ These initiatives provide empowering experiences for people who have felt marginalized and left out of everyday communal life. They also allow the participants to come to know their community better, and to feel that they are becoming better known as well.

However, these experiences primarily occur within the safety of New Growth or the Second Avenue community. Even in the neighborhood, where individuals with disabilities feel comfortable and welcomed in local establishments, there is a sense of insularity. When visiting a former resident in a rural part of the state, Nicole described how she recognized just how much of a bubble had been created around Lyth when an elderly man approached them at an after -church potluck:

And he kind of looked at us and he said ‘Somebody’s gotta be with him all the time don’t they,’ and I said ‘Yep, and we enjoy it.’ We enjoy being around him. ... I don’t know if it’s, in the big picture of things it is good that we’ve created this ... I mean we’ve learned the hard way about bubbles and living in bubbles this year, but I don’t think this is a terrible bubble to be living in (Nicole, Personal Interview, 2/2/2017).

The bubble is created largely because while attitudes that marginalize persons with disabilities have improved during the last 50 to 100 years, there are still those that do not see people with disabilities as necessary for the functioning of the larger society:

I think it just has to do with a broader kind of like how do we as a society hold views ... it started with ok we're going to put people with disabilities way over here; now we're going to care for them a little better, but still keep them over here ... and now we're kind of moving into integration (Cormick, Personal Interview, 2/3/2017).

That integration is necessary if many people in the larger community are to recognize the injustice inherent in their norms and beliefs. For Cormick, inviting people from the outside into the spaces of New Growth and Second Avenue through formal activities or through casual dinner or time on porches, helps to bring a unique experience of Jesus to people through those who have long been marginalized. A more formal experience volunteering at New Growth enlightened him to the struggle of people with disabilities, and inspired him to want to live in a community like Second Avenue:

I want to be in a community with people who have been marginalized...Because I wanted to be a part of a community that was formed around Jesus and so I could sense that presence of people that had experienced marginalization is essential ... it's an essential element of community around Jesus because I think Jesus is present in that struggle (Cormick, Personal Interview, 2/3/2017).

This testimony to the struggle and value of remedying society's propensity to hide persons with disabilities reinforces New Growth and Second Avenue's goal of creating spaces for people to flourish, and of not being content to retain those feelings and experiences within the confines of a single community. According to Margot, because individuals with disabilities make up the largest, most diverse (in age, race, and gender)

and most marginalized minority group in the country, it was imperative that the work of FBO's extend beyond the walls of the New Growth Center:

We just realized more and more our larger community cannot flourish if a whole population of people who have so much to give are kept so effectively at the margins. And so, I think that we do feel a sense of responsibility and longing to both bring the community into the New Growth Center ... where people can come in from the outside and have even just a momentary interaction with a person with a disability ... and then also going out into the community where again people can have a one-time event that might just turn their whole perception upside down ... The thing that's so surprising is that you do not see them in your day to day life. It is the most marginalized in terms of actual physical presence amongst the community of anything ... it's absurd because there's so many—the fact that they're hidden doesn't mean that they're not deserving of attention, it means they need more attention (Margot, Personal Interview, 2/21/2017).

Such a change of heart in the larger community, however, requires a creative reimagining of disability and community that Margot argued has so far been largely absent among traditional housing providers, but was nevertheless the catalyst for Second Avenue's development. By viewing people with disabilities as equals in relationships with persons without disabilities, the sort of mutuality that exists at Second Avenue creates a safe, affordable, encouraging environment for persons with disabilities to experience personal development and agency to the extent of their capacities to do so.

Young's criteria for participatory inclusivity suggest that it is necessary for a socially just democracy to recognize that some people have been taken advantage of and have lived in situations of injustice and marginalization (Young 1990, 124). A truly equal, democratic group needs to realize this fact of human existence and make accommodations for these people who have historically been the target of unjust behaviors, and grant them an equal say in governance and community. Both New Growth's framework and theological understanding of human dignity and the governing

ethos and informal, everyday environment of Second Avenue help to provide just such experiences for people with disabilities.

### **Authority Ultimately Derived from God Resides in Everyone**

According to Young, authority over oneself and an equal understanding of human dignity for all must be honored for a society to be democratically just and inclusive (Young 1990, 31). Everyone must have the chance to make decisions for themselves and exercise authority in decision-making for the community. At New Growth and Second Avenue, authority is understood to originate from God, so that any norms or rules, formal or informal, must reflect that understanding. In this view, because everyone belongs to Jesus, everyone has authority through Jesus over themselves and should get to make decisions for themselves. This is equally true for volunteers and participants. This orientation can be uncomfortable for persons without disabilities when they first come to New Growth or Second Avenue to volunteer or simply spend time and can create considerable consternation on their part. But, in fact, the FBO's governing norms generally demand that staff and volunteers ensure that they approach their leadership responsibilities with humility and a companion desire to allow individuals with disabilities truly to direct the course of the organization. At Second Avenue, this occurs through each individual's ability to direct the course of their own daily life by pursuing their own identified interests, education, and employment opportunities in addition to taking on leadership roles within the neighborhood and at New Growth.

Both the residents of Second Avenue and the staff at New Growth explicitly recruit individuals with disabilities to assume positions of leadership, although in many cases it requires a certain amount of time and training for those people to feel effective in



their roles. Participants have had a variety of authority figures in their lives, some of whom have treated them poorly or have not allowed them to assume responsibility for their own lives, let alone anything else. However, when staff members are able to match a participant with a leadership role involving activities they are excited about, the effect is striking:

I think the most basic and probably most important one is a sense of pride like 'this is my thing.' And ownership ... I think it's also a learned skill to know how to be on a leadership team (Mark, Personal Interview, 2/2/2017).

Formal chances for leadership allow individuals with disabilities to develop capacities that can transfer to other opportunities. Victoria, for instance, through her experience on the Community Worship leadership team at New Growth not only recognized her love and talent for singing, but also was able to take that knowledge and apply it to her life in Second Avenue. She is a frequent leader of morning and evening worship, and is the first to volunteer to lead others in impromptu group sings.

Victoria's personal feelings of empowerment and agency are derived from her strong faith, which she told me in her interview has flourished in the New Growth/Second Avenue community:

I have always been a strong believer in God, but it was hidden when I was home because my mom didn't go to church ... she would try to keep me from going to church or bible study or being in the church choir. ... I felt very isolated. ... I wanted to do things but my mom was keeping me away from the world ... as in not being able to express myself, being afraid to tell people that like you hurt my feelings (Victoria, Personal Interview, 2/11/2017).

Victoria suggested that living in this community has allowed her to have her own goals, but also help her friends and neighbors realize their full potential as well:

I was free in being able to be an adult ... any goals that I come to this community

about, they're going to try their hardest to help me complete those goals. ... God put me here to help, I have a purpose to be here. God put me here to love everyone. He put me here to love everyone regardless (Victoria, Personal Interview, 2/11/2017).

Victoria, along with many other Second Avenue residents—with and without disabilities—with whom I spoke for this study believe that their sense of purpose and agency ultimately derives from God and their identity as belonging to Christ. They believe this authority allows them to choose how and if they want to share their faith experience with others, and how much and in what capacities they want to be a part of the larger community. Tom, for instance, described how his work schedule did not permit him to spend as much time in the community as he would like, but when he is able, he uses some of the time he would normally spend doing something more “selfish,” to support the broader community. For Tom, Second Avenue represented a different understanding of authority than that to which he was accustomed:

You have authority over yourself, but you get to choose to give some of that up to serve people in your community. You also get to choose when to ask for assistance rather than have it just be bestowed on you out of pity (Tom, Personal Interview, 2/3/2017).

He found this view compelling and fulfilling because of his understanding of autonomy originating from Christ:

Christianity is obeying because you love God. ... Christianity is that God loves you so much that you do it out of so much love for Him (Tom, Personal Interview, 2/3/2017).

This theme of sacrificial love originating in love for Jesus is mirrored in the roommate relationships within the broader Second Avenue neighborhood; especially at the Edges House, where this way of thinking has been codified in a formal set of criteria that describe the vision of the house. These criteria, called “be abouts” are a set of

characteristics that Cormick described as flowing out of the person and the work of Jesus (Cormick, Personal Interview, 2/4/2017). This mentality has also influenced how people without disabilities living in the Second Avenue cohousing community view their relationship as roommates to those with a disability:

They're not taking care of those friends, they're living together as roommates and that's just a mind shift ... and once that happens like all these other things start happening ... natural seeming things and challenges that most roommates have to figure out (Nicole, Personal Interview, 2/2/2017).

For most members of the New Growth/Second Avenue community with disabilities, their first experience exercising God-given authority over their life occurred when they made a conscious choice to become a Christian outside of their living environment with their parents or guardian. When Tom decided to become a Christian after living outside of that faith for a few years, he found that this understanding of authority from God allowed him to shape how he saw himself and his own personal struggles:

I tried to make an independent move for myself because with Asperger's, you have a certain idea of ... I needed to be independent, but I had walked away from Christianity pretty much ... [when] I actually went to church ... I actually picked out a big large evangelical church ... but I wanted to go to church and I had a quiet moment and I just asked God into my heart and became a Christian then (Tom, Personal interview, 2/3/2017).

For Samantha, meanwhile, the chance to choose her own church and faith community allowed her to think about independence as coming from making your own choices, but also realizing that you can elect to rely on other people and go to them for help without having them treat you with pity or judgment (Samantha, Personal Interview, 2/10/2017).

It is this sort of mindset that New Growth hopes to cultivate through its

programming and use of space. When individuals with disabilities are given the chance to reach out and initiate friendships with people with and without disabilities, they are given a sense of confidence and ownership:

The growth that we've seen in some people and some people have stated in just social interactions and feeling comfortable around people and talking to people and just a better ability to be able to express needs and emotions ... just like having support and friends and community—some people who come here come from being at home and interacting only with their family and just don't even know how to or feel comfortable interacting with anyone else, and so they get to go from being lonely to having friends (Michelle, Personal Interview, 2/2/2017).

With the shifting definition of relationships comes recognition that an individual with a disability may be better able to model what it means to be a good friend to someone than a person without a disability.

Second Avenue, as a housing center, functions the way it does because of the desire for independence shown by the persons with disabilities who reside within it. Everyone who lives in Second Avenue, contrary to other housing options for persons with disabilities, has made the conscious choice to be a part of the community:

We want to be here. We want to live together...like real relationships and real friendships. That's the key ... the temptation is to be self-centered and self serving, and probably being a part of any community helps with that (Cormick, Personal Interview, 2/3/2017).

By recognizing and disciplining the part of himself that desires to live totally autonomously and have no responsibility to other members of the community, Cormick has consciously sought to develop a humbler lifestyle that recognizes the authority and value of every person (Cormick, Personal Interview, 2/4/2017). For individuals without disabilities, this often requires an uncomfortable amount of self-reflection. Lavender came to live in Second Avenue as a New Growth fellow shortly after graduating with her

Bachelor's degree, where she felt she was:

... told just to like look at yourself and do whatever you want to do and make the most of your own world, and then to come to a place like this and realize that you're so much more free when you're living with and for other people in mutuality ... we're missing out on the fullness of ourselves when we're not living closely with other people (Lavender, Personal Interview, 2/10/2017).

This understanding of independence suggests that such a condition is most fully achieved, paradoxically, by living in interdependence. Young has contended that, "having and exercising the opportunity to participate in making collective decisions that affect one's actions fosters the development of capacities for thinking about one's own needs in relation to others" (Young 1990, 92). However, individuals without disabilities in the neighborhood find that they must actively remind themselves to react to situations involving their friends with disabilities with humility. Cormick described, for instance, how a new resident wanted to go for a walk unaccompanied. He had to consider whether he was engaging in a patronizing behavior or expressing genuine concern for a friend about their going out alone in an unfamiliar environment. He asked himself whether he would have suggested he take someone along with him if the resident did not have a disability, and chose instead to let the resident decide for himself whether to go on the walk (Cormick, Personal Interview, 2/4/2017).

The staff of New Growth actively tries to engage in cultivating humility in order to put individuals with disabilities in the frame of equality:

Humility is a way of seeing, a way of rightfully seeing yourself as not above or below another person but equal to ... what is unique about this place is that it's not a program where one group is serving another necessarily, so we do our best when we can not to distinguish between volunteers and participants. We try our hardest to blur the lines (Carly, Personal Interview, 2/2/2017).

The model of inclusivity embraced and evidenced in this community meets Young's criteria for participatory justice because New Growth and Second Avenue residents, staff and volunteers seek to ensure everyone equal standing in decision-making (Young 1990, 91). No one person's opinion has more authority than another, and no one group holds control. People in this community with disabilities are given space and opportunity to make decisions for themselves and advocate for their own interests, because they are understood to possess authority over themselves.

### **Importance of Formal and Informal Opportunities to Express Agency**

Both New Growth and Second Avenue evidence formal and informal activities that encourage personal agency for people with disabilities. However, representatives of both entities said in interviews with me that they recognized formal opportunities help plant the seeds and provide the skills for agential development, but informal experiences outside of the community context are key to helping to cement a sense of empowerment for individuals with disabilities.

New Growth also brings the work their staff, volunteers, and participants are doing to the larger community through formal events such as Community Worship and the New Growth Talent Show. The talent show takes place each year at a large performance space and not at the New Growth Center. This is done not just for reasons of ensuring adequate space (the New Growth Center simply cannot accommodate the crowds that show up for the event), but because holding the event off-site helps to make the work and talents of participants known to a completely different neighborhood. The event, however, has become so popular that it is now held at the city's major, regional

performance center, which New Growth's leaders hope will attract an audience from an even wider geographic area, and allow participants to invite as many of their friends and family members as they wish (Michelle, Personal Interview, 2/3/2017) (Margot, Personal Interview, 2/21/2017).

Allowing participants to play the role of welcoming host is just one of the ways that New Growth aims to open spaces to people with disabilities that they do not traditionally occupy. One individual, for instance, was not allowed even to go into the kitchen in the group home in which she was living, even though she had expressed a desire to learn to cook. At New Growth, she was not only able to go into the kitchen as a part of New Growth Café, but also given the chance to experiment and improve her cooking skills. The opening of the kitchen for this participant, within the formal environment of the New Growth Café, allowed her to learn a set of skills that have allowed her to exercise agency and increased independence. This program participant has since moved to a location where she is free to spend time in the kitchen and further develop her skills, but it was through this activity that she was able to recognize her abilities and interest that later would prove transferable to her new living environment.

Relationships at New Growth also often begin through very formal mechanisms, but developing those ties to a point where they no longer need such structure to maintain and deepen them is the FBO's ultimate goal. When these relationships go from planned to unplanned, it demonstrates that both participants and volunteers have begun to see one another as equals, and the hierarchy of volunteer-participant is disappearing. For many of New Growth's program participants, the only non-paid and unstructured relationships that they have outside of their family are formed through the FBO. Lavender, for

example, told me how struck she had been while visiting the community early in her tenure as a volunteer at New Growth, by how individuals she had previously spent time with in a very formal setting (both with and without disabilities) lived in this very 'normal' environment. She noticed that all of the people felt connected to one another because they had met through New Growth and established a commonality through their experiences at the Center and that this commonality had created a sense of interdependence and trust in one another:

I think there's also like another way that faith plays out here is like dependency like the idea that we are all very dependent on one another and that's. ... I mean on a spiritual level but it's also very much tangible in just like we don't own everything so we have to our neighbors and ask to borrow something or like we all ... like two weeks ago there was a big group of us working to build the table for the corner house like there's just projects that people come together to do and people are very quick to say like 'I can't do this alone' I need help. Like Margot will send out like I need 3 strong humans to take a washer up the steps or something you know. It's just like ... a really clear understanding that we're only who we are because we can depend on one another. And we're stronger because of it (Lavender, Personal Interview, 2/3/2017).

The creation of these sorts of meaningful friendships and the desire to live them out in a more informal environment prompted development of Second Avenue, according to Margot:

... So many people with disabilities living in isolation and being lonely and not having anything to do or any (laughs) other than—the typical person with a developmental disability, often the only people who spend time with them are people who are paid to teach them something or change them in some way, and so or to manage their life in some way (Margot, Personal Interview, 2/21/2017).

Second Avenue, in many ways, creates a more informal space in which individuals who live there are able to employ some of the personal knowledge they gain from being a part of New Growth. They are also able to experience a very uninhibited living environment because they have trusted friends they can count on for support when



they need it, and assistance with certain daily tasks as they may require it. Meaningful friendships lived out informally create this possibility because:

Second Avenue, with the intimacy of living together, and New Growth, just with having so many people connected, has made lots of our friends' familiar faces around town. ... I think Second Avenue enables that in a different way because again they live together or near each other. People with disabilities live all over the place, but I think the imagination is not there for it to be a really natural connection (Mark, Personal Interview, 2/2/2017).

Second Avenue does also have its own formal structures and rhythms that allow for relationships to grow among neighbors. Multiple residents emphasized the importance of front porches in their interviews with me, and how certain members of the community are always outside on their porches and ready to invite you over for a drink or just to chat (Lavender, Personal Interview, 2/10/2017) (Samantha, Personal Interview, 2/10/2017) (Nicole, Personal Interview, 2/3/2017) (Cormick, Personal Interview, 2/4/2017) Nicole described how she and Lyth were out for a walk when the Agape House residents were moving in for the school year, and she noticed that one of the new students had brought a grill and placed it on the porch. An impromptu cookout immediately started, and she described how natural it felt because of everyone's desire to get to know and develop relationships with all members of the community—including the newcomers.

Informal relationships also helped to create smaller circles of support within the two communities. Edges House residents, for example, were given the chance when they moved in to designate a group of people that they knew and trusted to function as a support system external to the House community. Those individuals largely chose people whom they knew through New Growth. Few had trusted contacts besides family beyond the organization. For the staff members I interviewed, this reality underscored the

importance of encouraging such meaningful friendships to develop (Michelle, Personal Interview, 2/3/2017) (Carly, Personal Interview, 2/3/2017) (Mark, Personal Interview, 2/3/2017). It is important that participants be able to reach out to someone without a vested interest when they need someone in whom to confide (Cormick, Personal Interview, 2/4/2017)

Informal relationships also help to expand the physical environment of people with disabilities. For those who live in Second Avenue, this most often means casual trips to surrounding restaurants, the farmer's market, the local ice cream shop, and coffee shops. They can be seen frequently at these places, often accompanied by friends they had met at New Growth. For Cormick, the experience of sharing the built environment with his friends with disabilities has transformed the larger community as well:

But I also think like you look at something like the talent show and you see the [local] theater being packed out for an event like that and this year it's being held at [the regional performing arts center] and then you just think about all the people that have been drawn into New Growth Ministries as volunteers and participants who are experiencing a place of belonging and having the way that they see changed to the point where we're starting to see one another as all valued members of our community. And not just certain people just need other people to help them, but seeing the ways that we all need each other. And just starting to recognize the gifts that different types of people bring and that's a really hard thing to quantify (Cormick, Personal Interview, 2/3/2017).

The locations of both New Growth and Second Avenue help to encourage this sort of interaction with the surrounding environment: both are situated in downtown (though in adjacent but different neighborhoods), and are easy to get to by foot. Wheelchairs and other mobility devices, however, are not as easily accommodated. However, challenges in the built environment provide an opportunity for a person without a mobility impairment to share that experience with a friend who may have

trouble moving around – they can provide rides, a helpful push up a hill or over a curb, or merely come to understand the frustrations associated with riding the local wheelchair-accessible bus. Relationships help individuals who have typically been ignored or kept out of these everyday experiences be more engaged in the formal and informal spaces outside of their immediate community.

The importance of formal and informal spaces to express agency aligns with Young's criteria, because in order for a person to be fully included in the community, they must have access to all of the areas in which decisions affecting them can be made, and that includes formal as well as informal spaces, in addition to formal decision-making bodies. Formal relationships and opportunities for agency that people develop through programming and activities at New Growth can then be enjoyed and exercised, offering individuals with disabilities the opportunity to see for themselves where they can take control of their personal experiences and express personal agency in the larger world.

## **Chapter 5**

### **Conclusions**

#### **Contribution to the Literature**

Although I used a political framework to describe the approach to encouraging personal agency and democratic inclusion I examined in this study, it became obvious almost immediately that for these organizations, this conceptualization had to be interpreted in light of the theological terms they employ daily in their community. New Growth and Second Avenue were the product of faith organizations and each ultimately grounded their goals and vision in the precepts of Christian teachings. While these translated neatly to Young's framework for my analytical purposes, I believe they are worthy of study for their own sake and for their theological import.

The theology of disability literature largely focuses on the inclusion of persons with disabilities within the Christian church community and its operations understood broadly. This orientation implies that a person with a disability can express their capacities fully through involvement solely with the church, but the New Growth and Second Avenue collaboration suggests otherwise (Swinton 2011). The prevailing theological mentality, however, continues to assume that individuals with disabilities are 'special cases' when they leave the confines of the church. But as Lyth and others profiled here daily demonstrate, that is not and need not be the case. As Brock has argued, the challenge is very different from assuring inclusion in congregations. It is rather to ask, "How do we understand the church and so humanity when we receive

people with disabilities not as special cases, but as the rule of the church's truest gathering" (Brock 2012, 17)?

In short, while faith communities need to be more cognizant and equitable in how they treat persons with disabilities in their congregations, they need also to realize that those individuals need to be able to exercise the agency that their faith and sense of community with their congregation help them recognize in the greater environment in order to change hearts and minds.

One of the ways that the relationship between political and theological frameworks of democracy I traversed in this thesis can be understood, is through a lens of hospitality. This interpretation not only implies a theory of relationality that encourages individuals to see themselves as having a responsibility to a larger community, but also provides a framework for understanding human dignity. As Newman has suggested to members of his faith tradition,

as Christians, we need to ask in what ways have we come to see ourselves as autonomous agents pursuing our own self-interest, relying on the state to guarantee us freedom ... ought we accept such politics as formative of the body of Christ? (Newman 2007, 127).

Reflecting on one's own understanding of autonomy in light of the precepts of one's faith can have significant implications for how one sees him or herself in the larger polity.

Those views can have implications for public policy as well. The major share of lawmakers and administrators developing and implementing policy that affects individuals with disabilities do not themselves have a disability, and likely do not

encounter persons who do often in their day-to-day life. One reason for this is the current spatial isolation of these people from the rest of society. Providing this population opportunities to express agency only within their homes or in faith settings does not provide the rest of society a chance to understand what it means to be inclusive and recognize the inherent worth and dignity of these people. This is where it becomes vital that elected and appointed leaders provide a political framework to encourage the broader population to become more conscious of its fears and assumptions concerning those with disabilities, and to provide opportunities for those people to overcome the former and rethink the latter. For individuals with disabilities, “self-respect names not some possession or attribute a person has, but her or his own attitude toward her or his entire situation and life prospects” (Young 1990, 14). Such a change in orientation requires a rethinking of human dignity in a way contrary to today’s neo-liberal frame and sensitive lawmakers could play key roles in pressing for such a reorientation.

At the very least, a framework is needed that explains how the preponderance of people in society can come to understand human equality and dignity in a way that also recognizes the deep human need for relationships. Because the current prevailing social imaginary prizes autonomy and independence, further exploration and research should be conducted to provide reasoned descriptions and explanations for how relationships affect the experience of democratic expression. Young’s framework recognizes each person’s right to influence decisions, but to realize that aspiration in daily life, people in society must come to see all people—regardless of their differences—as inherently equal on the basis of a shared moral standard beyond today’s too frequent invocations of skin color or ability to work. Marginalized persons need to be able to see themselves as worthwhile

and respected by a society that understands inclusion in meaningful relationship. If you only see a person different from you at a once-a-month meeting, it is unlikely that you will find yourself thinking of their needs as equal to your own. The theological framework emphasized by New Growth and its collaboration with Second Avenue helps reframe exactly this phenomenon. By encouraging people to recognize the strengths and weaknesses in themselves and one another, they have created an environment of profound respect and mutuality among people with vastly different life experiences. Perhaps one central lesson of this study of a dedicated community of men and women is that meaningful relationships can truly have an impact on how all people in society see themselves. Positive self-consciousness appears to be a requirement for true inclusivity and any prospect for broad change in how our society treats its individuals with disabilities.

The collaboration between the New Growth ministry and its various entities and the cohousing community that grew out of it has created a unique environment for people with disabilities to experience agency and belonging. The lens through which New Growth and Second Avenue view personhood, personhood among the collect and personhood in society encourages individuals with disabilities to see themselves as important to God, significant to their friends and essential to society as a whole. Those I interviewed all shared three major perspectives that together appeared to be critical in creating this inclusive environment. I next turn to a brief review of each precept in turn.

### **A Differentiation between Theological and Practical Belonging**

This distinction arose at the founding of the organization as a part of the

disagreement between its founders and the national group from whom they had split. Theological belonging suggests that individuals first belong to Christ through His death and resurrection, and once they know this truth, they can begin to exhibit belief in God and themselves in the knowledge that they are redeemed and loved. Conversely, practical belonging suggests that individuals must first recognize their own depravity and sinfulness and make a conscious decision to let go of such attitudes and practices in order to belong to the fold of God. New Growth and Second Avenue both adhere to an understanding of Theological Belonging, which their leaders believe allows for expression of the diversity of capabilities and personalities that are innate to the population of those with disabilities. New Growth's leaders also contended strongly that Practical Belonging is too dogmatic in its approach to salvation and understanding of faith.

### **Mutuality and Equality in Belonging**

New Growth and Second Avenue leaders argued in their interviews that because all individuals are included in salvation regardless of their ability to conceptualize that truth, all people in the community have a responsibility to treat their friends equally and encourage their personal agency (Carl, Personal Interview, 2/7/2017) (Margot, Personal Interview, 2/21/2017). Individuals, whether characterized by disabilities or not, do not experience life in a fully autonomous environment. While all people in our society possess wide authority over their personal selves, most recognize early in life that they are capable of living a fuller life when they choose to relinquish a modicum of independence to live in relationship with one another. Residents, staff, volunteers and program participants of New Growth and Second Avenue seek daily to realize this



aspiration.

### **Contextual vs. External Agency**

Individuals with disabilities can be given ample opportunities to express themselves in the cultivated environment of New Growth, but it was through expressions external to formal programming that my interviewees suggested that those with disabilities and those without them truly realized inclusivity. This occurred partially through Second Avenue, which serves as a more informal contextual space that offers opportunities for individuals to express themselves outside the community in the knowledge that they have a neighborhood that will support them on their return. However, staff, residents and volunteers all recognize that society's dominant social imaginary must change before persons with disabilities can experience true inclusion. Opportunities for participants to express agency beyond the New Growth and Second Avenue environments that nurture them are what truly help to change public perceptions of persons with disabilities.

The cultures of the two entities I studied embrace the view that every person has inherent worth and gifts. Each also argued that societal narratives of independence and the ability to work as a central yardstick of human worth must be changed to allow for every person, regardless of whether they have a disability, to experience a sense of agency. By framing relationships as vital to the flourishing of all, each person who works with New Growth or lives in the Second Avenue Community is encouraged to recognize that they possess both strengths and weaknesses and innately need others to assist them when they lack specific capacities or otherwise fall short. Such an attitude is unusual, not just for general society, but especially for providers of services for persons with

disabilities.

Too many such organizations are organized to offer services to those with disabilities to secure financial profits. In contrast the entities profiled here have embraced an approach to relationship exemplified by relational-based care for persons with disabilities. That perspective could not be more different in what it values and how it treats those with whom it works than the prevailing utilitarian and instrumental frame. derived from finances or numerical indicators and benchmarks.

Because New Growth and Second Avenue approach their service offerings through the idea of mutuality, those working with these organizations also exhibit a markedly different conception of what constitutes charity, service and volunteerism. A ride across town for a person unable to drive, for instance, may cost \$5 or \$6 dollars and three hours of planning and travel time without a friend to take one there. For someone capable of driving, providing this service to a friend does not constitute something for which they need to be compensated, but rather, is a task undertaken out of love and respect. In the end, mutuality creates a win-win situation for all people involved in the community as those with and without disabilities begin to share a purpose and come to a deeper self-awareness of their own needs and strengths.

Staff, residents and participants expressed concerns about the relatively sequestered character of these communities in their interviews with me, and the problems that can present for persons with disabilities when they seek to exercise the sense of agency they enjoy in the Second Avenue neighborhood beyond its confines. Because feelings of fear, misunderstanding or discrimination still exist so pervasively in the larger society toward people with disabilities, it is still often quite difficult for such individuals

to feel free to express themselves outside of their home areas. This fact highlights the need for social change that will allow these populations opportunities to express both contextual agency (through formal and informal activities among peers) and external agency (outside of their immediate frame).

Contextual agential opportunities help individuals with disabilities develop the skills and awareness necessary truly to flourish as who they are. Both New Growth and Second Avenue provide such ‘contextual’ environments because people who understand the importance of their friend’s personal agency largely populate them. But these places should not comprise the entire experience for persons with disabilities. In order truly to enjoy maximum opportunities to grow and realize their capacities to the fullest extent possible, they must be able to move outside their home community and not be subject to discrimination, fear or harassment.

Opportunities for external agency for residents of Second Avenue (and by extension, all individuals with disabilities) can vary widely, but ultimately, they need to engage people who are unaffiliated with their organizations or families. New Growth provides some formal opportunities for this through the New Growth Talent Show and New Growth Café, but the most fulfilling expressions of agency will come when a person exercises the agency of which they have become conscious at New Growth to fulfill a life goal such as completing a specific exercise goal, or obtaining a job at a local business or pursuing higher education.

It would also be positive step to bring still more people external to the organization in to experience the contextual environment of New Growth and Second Avenue. Partnerships with the local churches many of the participants attend is one of the

strategies that New Growth employs to give people a chance to see how its efforts differ from those of other disability support organizations. The experience of seeing persons with disabilities in leadership and hospitality roles provides those in these congregations a chance to change their perceptions of people with disabilities. While doubtless a small step in the grand scheme of American society, such shifts are essential to any prospect of more widespread change in how the broader citizenry views individuals with disabilities.

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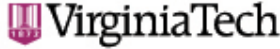
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# Appendices


## Exhibit A: Research approval letter from the Institutional Review Board



**Office of Research Compliance**  
Institutional Review Board  
North End Center, Suite 4120, Virginia Tech  
300 Turner Street NW  
Blacksburg, Virginia 24061  
540/231-4606 Fax 540/231-0959  
email [irb@vt.edu](mailto:irb@vt.edu)  
website <http://www.irb.vt.edu>

### MEMORANDUM

**DATE:** February 2, 2017

**TO:** Max O Stephenson Jr, Natalie Rose Patterson 

**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)

**PROTOCOL TITLE:** Creating Participatory Space through Partnership: Exploring the relationship between a faith-based day programming organization and a cohousing community for individuals with and without disabilities

**IRB NUMBER:** 16-1155

Effective January 19, 2017, the Virginia Tech Institutional Review Board (IRB), at a convened meeting, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at: <http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

### PROTOCOL INFORMATION:

Approved As: **Full Review**  
Protocol Approval Date: **January 19, 2017**  
Protocol Expiration Date: **January 18, 2018**  
Continuing Review Due Date\*: **December 25, 2017**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

### FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

*Invent the Future*

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY  
*An equal opportunity, affirmative action institution*

## **Exhibit B: Interview questions for study participants**

### *Cohousing Community Resident Questions*

1. Please describe for me how you see your role in your cohousing community? Do you think your voice is heard and you have an equal say in decision-making for the development? Can you provide me with an example (or more if you wish) of a decision of which you have been a part?
2. In what activities do you participate in the community?
3. What/where are the places that you spend the most time? Where do you spend time alone? With friends? What sort of activities do you do with those friends? Where do you usually hang out with them?
4. To whom would you turn if you had a problem? How would you seek to reach them?
5. Do you participate in activities outside of the community in which you live? If so, can you share examples of those with me? How did you get involved in those programs or undertakings?
6. Can you provide me one or more examples of when you believe you expressed “personal agency” (a sense that you could assert your point-of-view and could expect others to listen)? Do you think living in your cohousing development has helped you realize your personal strengths and goals? If so, how? Do you think the community collectively encourages personal choices and goal setting? Do community residents do so? If so, why do you think that is so? If not, why not?

### *Day-Support Program Participants who are also Cohousing Community Residents*

#### *Questions*

1. How would you describe your time spent at (New Growth)? What are some of the best



dimensions for you of participating in the New Growth day support program? Why?

What are some key items of knowledge you have learned at New Growth? Has this knowledge made a difference in your life? If so, how?

2. Who are some of your friends? How did you make those friends? What do you do when you spend time with them and how do you communicate (what forms do you use; please share all of those you can recall employing)? Do you mostly see these friends at home in the cohousing community or at New Growth or both? Is there a fluidity in these friendships between locations?

3. What are some difficulties you perceive you are confronting in fulfilling your personal and professional goals? How do you go about addressing those? Who do you work with to pursue your goals?

4. How would you say your life has changed, if at all, as a result of your participation in Second Avenue / New Growth and why?

#### *Day Support Program Staff Questions*

1. How did you come to work for New Growth?

2. What messages do you hope to convey to participants and volunteers? Why? How do you seek to convey those to program participants? Can you provide examples?

3. How do you (or do you) think that New Growth has had an effect on the larger community it serves? If so, can you share how you think it is doing so?

4. What are some common concerns participants have expressed to you concerning their living / working lives outside of New Growth? Do you think the Ministry addresses those in its programming? If so, how specifically?

5. Do participants help decide how New Growth is run? If so, can you provide examples

of how they do so and why? Do they influence the type or the way that programs are designed and implemented?

6. Do you include individuals with profound disabilities in your programs? If so, why? And how?

7. What sorts of rules or norms exist in your organization, if any, that seek to ensure a comfortable and welcoming environment for all participants? Do you and other staff members play any role in seeking to create a welcoming and comfortable role for those enrolled in your programs? If so, can you describe how you do so for me, please?

8. I noticed that New Growth's mission statement speaks of encouraging "meaningful friendships." Could you please describe for me what that means in practice; that is, how you seek to realize that aim? Would you say these efforts have impacts on your program participants and volunteers? If so, could you describe those for me, please?

*Day Support Program Board Member Questions*

1. How did you first become involved in New Growth?

2. What makes New Growth different from other nonprofits serving people with disabilities?

3. How would you articulate the current vision of the organization? In your view, does this vision intersect in mutually beneficial ways with the aims of the Second Avenue (cohousing) community, where a significant share of your clients reside? If so, can you share how and why this is so?

4. How would you describe the New Growth and Second Avenue relationship? Do you think the connection(s) between them should be increased, stay the same, or should they be made more separate? Can you share why you responded as you have?

5. What, if any, attributes in your view make Second Avenue unique as a living environment? What do you think are some of the ways space has been used in a unique way?

6. How have the cohousing community's residents surprised you? Have they changed your expectations or perceptions of certain programs, spaces, groups or opportunities? If so, how and why?



**VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY**  
**Informed Consent for Participants**  
**in Research Projects Involving Human Subjects**

**Title of Project:** Creating Participatory Space through Partnership: Exploring the relationship between a faith-based day programming organization and a cohousing community for individuals with and without disabilities

**Investigator(s):** **Max Stephenson** [mstephen@vt.edu](mailto:mstephen@vt.edu)  
**Natalie Patterson** [natpat@vt.edu](mailto:natpat@vt.edu)  
(269) 762-0298

**I. Purpose of this Research Project**

*This study will examine the relationship between a housing and day-programming center for people with disabilities. The purpose of this research is to understand how this relationship impacts the lives of individuals with disabilities, and to explore whether or not it provides these participants with opportunities for personal growth and expression in a unique way. Results will be submitted as a master's thesis, and may be published after acceptance by Virginia Tech. This research will be comprised of 15 individuals involved in both the housing community and day-programming ministry, and will include individual participants, staff, and board members.*

**II. Procedures**

*Should you agree to participate in the study, you will be asked to participate in a 45 minute audio-recorded interview. You will be asked questions about your feelings and experiences as a member of North Street and Reality. Organization names will be given pseudonyms in analysis publication to provide anonymity. You will be able to choose the location of the interview based on your accessibility and comfort needs. You will likely only be asked to participate in one interview, however, you may be asked a few follow up questions at some point after the initial interview. If you are an individual under legal guardianship, your legal guardian will need to provide consent on this form.*

**III. Risks**

*There are no expected risks or discomforts expected from participation in this research project. However, you will be asked to recall and explain personal experiences and feelings associated with your involvement in the communities of study. If there are unpleasant or uncomfortable memories associated with these experiences, you may experience emotional distress.*

#### **IV. Benefits**

*There are no direct benefits for participation in this study. However, your ward's open and detailed responses to interview questions may provide information regarding a unique environment that can be replicated in other communities.*

No promise or guarantee of benefits has been made to encourage you or the individual under your guardianship to participate.

#### **V. Extent of Anonymity and Confidentiality**

*Coded identities will be assigned to your ward in order to protect confidentiality. Transcripts of interviews will only be identified by their assigned code. The key to this code will be stored in a separate password protected file on a personal computer, which is password protected. Interview transcripts and field notes will be stored on the Virginia Tech Google drive system, and will also be password protected. All of this information will only be available to the principal and co-investigators. There will be no identifying information on these notes that would compromise your ward's identity.*

The Virginia Tech (VT) Institutional Review Board (IRB) may view the study's data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

#### **VI. Compensation**

*No compensation will be offered for participation in this study.*

#### **VII. Freedom to Withdraw**

*It is important for you to know that you are free to withdraw your ward from this study at any time without penalty. They are free not to answer any questions that you or they choose or respond to what is being asked of without penalty.*

*Please note that there may be circumstances under which the investigator may determine that a subject should not continue as a subject.*

#### **VIII. Questions or Concerns**

*Should you have any questions about this study, you may contact one of the research investigators whose contact information is included at the beginning of this document.*

*Should you have any questions or concerns about the study's conduct or your rights as a research subject, or need to report a research-related injury or event, you may contact the VT IRB Chair, Dr. David M. Moore at [moored@vt.edu](mailto:moored@vt.edu) or (540) 231-4991.*

**VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY**  
**Informed Consent for Participants**  
**in Research Projects Involving Human Subjects**

**Title of Project:** Creating Participatory Space through Partnership: Exploring the relationship between a faith-based day programming organization and a cohousing community for individuals with and without disabilities

**Investigator(s):** **Max Stephenson** **mstephen@vt.edu**  
**Natalie Patterson** **[natpat@vt.edu](mailto:natpat@vt.edu)**  
**(269) 762-0298**

**I. Purpose of this Research Project**

*This study will examine the relationship between a housing and day-programming center for people with disabilities. The purpose of this research is to understand how this relationship impacts the lives of individuals with disabilities, and to explore whether or not it provides these participants with opportunities for personal growth and expression in a unique way. Results will be submitted as a master's thesis, and may be published after acceptance by Virginia Tech. This research will be comprised of 15 individuals involved in both the housing community and day-programming ministry, and will include individual participants, staff, and board members.*

**II. Procedures**

*Should you agree to participate in the study, you will be asked to participate in a 45 minute audio-recorded interview. You will be asked questions about your feelings and experiences as a member of North Street and Reality. Organization names will be given pseudonyms in analysis publication to provide anonymity. You will be able to choose the location of the interview based on your accessibility and comfort needs. You will likely only be asked to participate in one interview, however, you may be asked a few follow up questions at some point after the initial interview. If you are an individual under legal guardianship, your legal guardian will need to provide consent on this form.*

**III. Risks**

*There are no expected risks or discomforts expected from participation in this research project. However, you will be asked to recall and explain personal experiences and feelings associated with your involvement in the communities of study. If there are unpleasant or uncomfortable memories associated with these experiences, you may experience emotional distress.*

## **Exhibit D: Recruitment Emails**

### **Recruitment Email for participants, staff, and board members not requiring consent from a legal guardian**

Hello,

My name is Natalie Patterson and I am currently pursuing my master's degree in Urban Planning at Virginia Tech. I am conducting a research study for my thesis regarding the relationship between New Growth and the Second Avenue Community, and how these organizations have allowed you as a participant, staff member, or board member, to experience personal growth. I am looking for about 15 individuals who are willing to participate in a roughly 45 minute interview at a location of your choosing to answer a few questions about your experiences and feelings about New Growth and Second Avenue. I have attached the consent form required for participation in the study that outlines more about the protocol and process of this research study. If you are interested in participating, or have additional questions, feel free to contact me directly.

Thanks so much!

Natalie Patterson  
Graduate Assistant - Graduate School Student Services  
Master's Candidate - Urban and Regional Planning  
Economic Development and Nonprofit Management Concentrations  
Virginia Polytechnic Institute and State University  
(269)762-0298

### **Recruitment email for legal guardians**

Hello,

My name is Natalie Patterson and I am currently pursuing my master's degree in Urban Planning at Virginia Tech. I am conducting a research study for my thesis regarding the relationship between New Growth and the Second Avenue Community, and how these organizations have allowed your child or the individual under your legal care to experience personal growth. I am looking for individuals who are willing to participate in a roughly 45 minute interview at a location of their choosing to answer a few questions about their experiences and feelings about New Growth and Second Avenue. I have attached the consent form required for participation in the study that outlines more about the protocol and process of this research study. Individuals under legal guardianship will need the legal guardian present at the interview, and the guardian will need to provide formal consent for the individual's participation. If you are interested in participating, or have additional questions, feel free to contact me directly.

Thanks so much!

Natalie Patterson  
Graduate Assistant - Graduate School Student Services  
Master's Candidate - Urban and Regional Planning  
Economic Development and Nonprofit Management Concentrations  
Virginia Polytechnic Institute and State University  
(269)762-0298



## Recruitment Email for Participants with developmental disabilities

Hello,

My name is Natalie Patterson and I am currently pursuing my master's degree in Urban Planning at Virginia Tech. I am doing research on Second Avenue and New Growth for my Master's Degree, and I am hoping to hear from you about your experiences at both of these places. I will be asking you questions for about 45 minutes at a place you feel comfortable being interviewed. There is an attached form that you will need to look over with a guardian (a parent or legal caretaker) carefully that says more about the study and your participation. If you would like to talk with me, or have any more questions, feel free to give me a call or email!

Thanks!

Natalie Patterson

Natalie Patterson  
Graduate Assistant - Graduate School Student Services  
Master's Candidate - Urban and Regional Planning  
Economic Development and Nonprofit Management Concentrations  
Virginia Polytechnic Institute and State University  
**(269) 762-0298**