Re-defining “accessibility” in community development: An appreciative inquiry for the 1 in 59 on the autism spectrum

Anita J. Montgomery

Iowa State University

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Re-defining “accessibility” in community development:
An appreciative inquiry for the 1 in 59 on the autism spectrum

by

Anita J. Montgomery

A thesis submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
MASTER OF SCIENCE

Major: Interdisciplinary Graduate Studies (Community Development)

Program of Study Committee:
Timothy Borich, Major Professor
Biswa Das
Daniela Mattos

The student author, whose presentation of the scholarship herein was approved by the program of study committee, is solely responsible for the content of this thesis. The Graduate College will ensure this thesis is globally accessible and will not permit alterations after a degree is conferred.

Iowa State University
Ames, Iowa

2019

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DEDICATION

To each of my children:
I will never be able to express how incredibly blessed I have been by each of you. I love you bunches.

To the autistics out there: You are loved and valued.
To the families: Care for yourself first. Pick your battles. Do what you can. And let the rest go.

I See A Hero

My hero is not a man nor woman.
My hero is but a mere child sent from God.
A boy of unimaginable abilities that most adults cannot begin to comprehend.
A boy that is shunned from the world because of his individualism.

People see a child with a disability.
I see a hero with a unique personality.
People see a child that cannot talk.
I see a hero that chooses not to talk.
People see a child that cannot be controlled.
I see a hero that does not wish to be controlled.
People see a child with funny teeth.
I see a hero’s smile bursting with pride.

People look into the boy’s eyes to see nothing for his future.
I look into my hero’s eyes to see it gleaming with blue seas of hope and forgiveness.
People listen to his words with closed ears and hearts.
I hear a hero’s song magnificently sung in a new language that has yet been discovered.

People see a vulnerable and weak child.
I see a hero that is ten feet tall and bulletproof.
People see a child with an easy life.
I see a hero’s troubles and sorrows greater than many people can ever begin to imagine.

My hero has taught me many life lessons.
My hero has untold accomplishments as well as untold hardships.
My hero looks at his unusual aspects differently than others.

While people may see this disabled child,
I See A Hero.

- T., 17 years old (Reprinted with permission.)

(An excerpt from a three wishes paper.)

My third wish would be a cure for any and every disability so that no kid or adult would have to go through being made fun of for how they look and act. The second reason I would want a cure for any and every disability is so that… when I go off to college I don’t have to worry about my mom taking care of him and then something happens to my mom. I don’t know where my little brother will go where he will be okay.

- S., 12 years old

(Reprinted with permission.)
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<tbody>
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<td>Achieving a Better Life Experience Act</td>
</tr>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>AI</td>
<td>Appreciative Inquiry</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>CCF</td>
<td>Community Capitals Framework</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Human Services</td>
</tr>
<tr>
<td>HCBS</td>
<td>Home and Community Based Services</td>
</tr>
<tr>
<td>I/DD</td>
<td>Intellectual and Developmental Disabilities</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Physician</td>
</tr>
<tr>
<td>PWD</td>
<td>Person(s) with Disabilities</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

There are many people who supported me along this journey whom I would like to take this opportunity to thank. Thank you to Dr. Timothy Borich who challenged and strengthened me to embrace theory and gave me the space to finally let this work go. Thank you to Dr. Biswa Das for going on this journey with me, through inclusive entrepreneurship, pushing me to question the quantitative data, and encouraging me to tell our story. Thank you to Dr. Daniela Mattos for your encouragement and for re-lighting a spark that I had lost. This work is a reflection of the passion each of you brought out in me along the way. Thank you to Nora Ladjahasan for guiding me through the Institutional Review Board process, and to other behind-the-scenes people who see all of us through our programs of study who may not always feel appreciated: Michelle Zander, Melissa Stolt, and Casey Smith.

A special thank you to Dr. John and Ruth McCully for your 30 years of friendship, support, and mentoring. I love you both. I survived! Thank you to my tribe -- the other equity/conflict “Musketeers” who so serendipitously began this journey at the same time as I -- Adam Reeck, Janice Edwards, and Chris Lempa. We survived!

There is a team who got our family where we are today: Dr. Peter Go, Dr. Rachel Bowman, Dr. Angela Shy, Carrie Pieroni, and Allison Moss. You listened, worked as a team and made a difference. We are incredibly grateful and consider you part of our family. To Kerry Evans and Lisa Morgan, you are family.

Thank you to Dr. Cherisse Jones-Branch, my sister-in-arms, who inspires me. I hear you. Thank you to Dr. Cornelia Butler Flora who befriended me and asked questions along the way. And a special nod to the ladies at Backgate One Stop -- Deanna, Brenda, LeAnne, Jerri, Whitney, and Alison -- who kept me fueled up and provided shoulders on which to cry.
A special thank you to my parents who gave me a dollop of stubbornness and a dash of compassion from the beginning and have had the patience of Job with me, not just in this endeavor, but in life. And, finally, to my children, you are my greatest achievements, my light in my darkest hours, and my greatest supporters. I have been blessed beyond measure.
ABSTRACT

The Center for Disease Control (CDC) recently estimated that 1 out of 59 children in the U.S. are on the autism spectrum (Autism Speaks, 2018), and one-half million children with autism are expected to become adults through the next decade. Compared to all other people with disabilities, autistic adults are more likely to be socially isolated, unemployed, and living in poverty. This research takes a positive approach, using Appreciative Inquiry (AI) and the Community Capitals Framework (CCF), to examine what communities are doing for adults with autism to address issues identified earlier, and what communities can do to enhance the life experiences of this group. Data was collected using an online survey and analysis findings point to strengths in human, cultural, social, financial, and built capitals. Archival records and researcher experiences were used to supplement the survey findings.
CHAPTER 1. INTRODUCTION

Background Information

This researcher’s son was 18 months old when he sat down and started beating his head on a concrete floor. When this mother mentioned it to the primary care physician (PCP) (there are no pediatricians in this rural, impoverished area of the nation), the response was, “Oh, he’ll grow out of it.” A year later, he was not talking like his two older siblings had done. Again, this mother told the PCP. His response: “He has two older siblings who talk for him.” That PCP was the first of many now forgotten doctors and therapists that this mother has fired over the past 19 years, primarily for, well, incompetence. The next PCP quickly referred Son to an ear, nose, and throat specialist for an audiogram. The diagnosis was asymmetrical, bilateral sensorineural hearing loss (severe to profound on the left side, and mild on the right side), but, as he said, “something else is going on.” Eight months later, suspicions were confirmed: moderate autism spectrum disorder. This researcher sobbed, not from grief of “losing” a typical child, but at the confirmation that this mother was not crazy.

Parents look to the specialists, therapists, and educators to be the experts in their respective fields – to know and actually do what is “best” for the child – not realizing that perhaps the ethics of the professional or the morals of the “expert” are not aligned with what is “best” or “right.” Many parents – perhaps more so those living in information deserts, who lack financial capital, and whose social capital are the gatekeepers to independence and pipelines to charitable day habilitation and sheltered workshop services – may rely on a doctor-prescribed witch’s brew, often prescribed off-label in the absence of behavior therapies, to address autism-

---

1 Sensorineural hearing loss results from inner ear damage or damage to the pathway from the inner ear to the brain. Hearing aids do no amplify decibels lost to sensorineural damage, only those decibels that remain intact.
related symptoms, such as aggression, hyperactivity, repetitive behaviors, cognitive challenges, and sleep disruption (LeClerc and Easley, 2015; Geggel, 2013). [Risperidone, the first medication approved for autism-related aggression in children five years old and older, was the subject of recent class-action lawsuits for enlarged breasts in men. Antipsychotics, such as risperidone, can also cause tardive dyskinesia, a potentially irreversible disorder that results in involuntary movements of the lips, mouth and tongue (Kim, MacMaster and Schwartz, 2014). Benztropine sometimes is prescribed to mask the tardive dyskinesia.]

Little is known about the long-term effects on developing brains from a single medication, let alone the interaction of multiple medications. Children in the southern United States are more likely to take more than one medication compared to children in the northeast and western United States, and one study found that 10 percent of infants under one year old who were later diagnosed with autism were also prescribed multiple medications (Geggel, 2013). Some parents will grasp at any dangerous autism “cure,” from exorcisms to oral bleach treatments.”

Others -- with knowledge and financial capital – will relocate and access life-changing resources.

For many students with autism, developmental, and intellectual disabilities at midnight the morning of their 22nd birthday they fall off “the cliff” (Roux, 2015; Sarris, 2014). Children in America who receive special education are guaranteed an education and its related services, including speech therapy, occupational therapy physical therapy, independent living skills, vocational training, and other services until they graduate or turn 22 if their respective state considers 21 to be all-inclusive. Parents of school-aged children are guaranteed a “free

2 For information on states’ efforts to reduce antipsychotic prescriptions via Medicaid, see https://www.medicaid.gov/medicaid-chip-program-information/by-topics/prescription-drugs/downloads/state-medicaid-dur-summaries.pdf
3 Exorcism: Sweetingham, 2004; Oral bleaching agents and bleaching enemas: Eltagouri, 2018, Mammoser, 2018; Chelation: Brownstein, 2010
appropriate public education” under the Individuals with Disabilities Education Act (IDEA), even if they must sue, contingent upon the resources to do so. However, things change when the child graduates or ages out of the school system. What services are available after graduation or aging out are dependent upon state Medicaid funding, and, although some services may be available, there may be long waiting lists, such as for Medicaid Home and Community Based Services waivers or housing (Galvin, 2018; Snow, 2015).

Additionally, without the structure and supports that many individuals with autism need, the skills that they have learned through the school-age years could result in regression and a worsening of their autistic symptoms (James, 2013). This transition to adulthood and searching for services and supports intensifies the ever-looming question for parents, “What happens to my child when I’m gone?” (Also, because adult programs are funded through state Medicaid programs, if an individual receives services in one state and moves to another state to live with siblings in the event of the aging or death of parents, that individual will be required to wait in line for services in the receiving state.)

**Conceptual and Theoretical Frameworks**

For this researcher/practitioner to present herself as an objective observer would be deceptive (Herr and Anderson, 2015). This researcher’s experience as the mother of a young man clinically diagnosed with Opitz-Kaveggia Syndrome, or FG Syndrome, (autistic-like tendencies, hearing impairment, verbally limited, epilepsy, ADHD, and diagnostically identified with intellectual disabilities) informs this thesis. The proximity to the disabilities community makes this researcher more than a technical assistant or even a participant observer, but, “…as an actor in those situations” (Ravitch and Riggan, 2017, p. 81). Fourteen years of journaling and social media posts will be used to explain and expand on the data. A first-person narrative will be used
in those entries because, in that moment, the researcher is the participant, and a third-person narrative diminishes that lived experience. This study is situated in critical social theory, and, thereby, critical disabilities studies (Meekosha, 2009), empowerment theory (Zimmerman, 2000), and, when necessary, conflict theory.

This mother watched her son become a psychopharmacological guinea pig in the early years but had the education and financial resources (the privilege) to seek out behavioral education and therapies when he was on the verge of institutionalization due to aggression toward others as a youngster. This researcher has been a volunteer parent educator and child advocate and was involved in a failed systems-change grant in a region where guarding systems is prioritized over outcomes. “The cliff,” which occurred before this research was published, was the impetus to study community development for the autistic community and wholly guides this research as an advocacy and equity planner who seeks a balance between a vulnerable population striving for self-determination and “first, do no harm.”

Ravitch and Riggan (2017), referencing other authors, state:

A significant challenge in designing and conducting research is to critically examine and make transparent, the goals, commitments, frames of reference, guiding concepts and theories, and working assumptions that influence your work… This means in part that how one approaches data collection – and, we would add, what one brings to the design and framing of the research as a whole – has much to do with the quality and content of one’s data and therefore has a significant influence on one’s analyses and findings. (p. 80)

---

4 After being on five prescribed medications and melatonin for sleep issues, Son has been on an anti-seizure medication, a low-dose anti-depressant, and 1 mg. of melatonin.
This researcher participated in her first walk-out in high school, and subsequent anti-apartheid sit-ins, based more on Thoreau’s *Civil Disobedience* and observations of the ‘60s and ‘70s than any knowledge of social science and Saul Alinsky. As Dahrendorf (2012) wrote, though, “Revolutions are melancholy moments of history. The brief gasp of hope remains submerged in misery and disillusionment…. Many are caught by a mood of elation. Not just the abuses of the old regime, but the constraints of society itself seem suspended. However, the honeymoon does not last. Normality catches up with people…. Individual circumstances are reflected in social conditions” (p. 1). The sociologist and political scientist, specifically speaking of the Civil Rights and Women’s rights movements in American, pointed out that civil rights gained are not guaranteed for those who do not have the economic capital to defend them. Nor are political rights guaranteed if individuals lack education or when the social and economic costs are too high. Dahrendorf overlooked the disability rights movement in his argument, but the argument still applies. Indeed, critical disability studies forms its roots as any other critical studies, and both the Rehabilitation Act and the Americans with Disabilities Act came about through conflict. Similarly, those children who appropriately benefit from the disability education law are only those whose parents know the law and have the economic resources to endure due process or the civil court system. Although some civil rights may have been gained on the pages of the federal code or in the Supreme Court, reality paints a different picture of opportunity as is shown in Figure 1. At once, it is a glass half full (political rights) and a glass half empty (economic and social rights).
### Key Disability Rights Laws & Court Decisions

| **The Rehabilitation Act** | **Realit**
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Passed by Congress, vetoed by Nixon, and resulted in sit-ins by persons with disabilities (PWD). The law passed in 1973. Section 504 of the law requires employers to provide &quot;reasonable accommodations&quot; for PWD in the workplace. Federal regulations were not signed until 1977 after another round of sit-ins (Rehabilitation Research &amp; Training Center on Independent Living Management, 2002).</td>
<td>Despite protections under the <em>Fair Housing Act</em>, families with autistic children and autistic adults face harassment and eviction as renters due to noise and property damage (Simon, 2014; Carter, 2010).</td>
</tr>
</tbody>
</table>

| **PL 94-142** | **ABLE ACT**
<table>
<thead>
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<th></th>
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<tbody>
<tr>
<td>The Education for All Handicapped Children Act, later renamed the Individuals with Disabilities Education Act (IDEA), guarantees free appropriate public education in the least restrictive environment for children with disabilities in schools receiving federal funds.</td>
<td>Program may be unsustainable due to insufficient number of accounts (Diament, 2018), just as myRA, a retirement program for low-income earners ended under Trump (Lobosko, 2017).</td>
</tr>
</tbody>
</table>

| **The Fair Housing Act** | **Olmstead v. L.C.**
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>Amended to prohibit discrimination against PWD and families with children (Rehabilitation Research &amp; Training Center on Independent Living Management, 2002).</td>
<td>SCOTUS ruled at &quot;undue institutionalization qualifies as discrimination 'by reason of...disability,' violating Title II of the ADA, and that institutionalization &quot;cannot be justified by a lack of funding&quot; (Legal Information Institute, n.d.).</td>
</tr>
</tbody>
</table>

| **Americans with Disabilities Act (ADA)** | **ABLE ACT**
<table>
<thead>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Following &quot;the Capitol crawl,&quot; where PWD crawled the steps of the Capitol, including an infamous picture of then-8-year-old Jennifer Kellan, the most sweeping civil rights law for PWD became law (Eaton, 1990). It required all government programs and private businesses to be accessible. It also required accessibility to public transportation and communication (Rehabilitation Research &amp; Training Center on Independent Living Management, 2002).</td>
<td>Allows PWD to save up to $100,000 for certain expenses without losing Social Security and other government benefits (Diament, 2018).</td>
</tr>
</tbody>
</table>

| **Olmstead v. L.C.** | **Roll back of the Affordable Care Act threatens Home and Community Based Services for PWD via cuts in state Medicaid (Solomon and Schubel, 2017).**
<table>
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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>SCOTUS ruled at &quot;undue institutionalization qualifies as discrimination 'by reason of...disability,' violating Title II of the ADA, and that institutionalization &quot;cannot be justified by a lack of funding&quot; (Legal Information Institute, n.d.).</td>
<td>After the Department of Justice began moving away from sheltered workshops (segregated work environments for PWD) in 2014, the Trump administration rescinded the DOJ guidance documents (Perry, 2018). Legislators begin to address an 80-year-old loophole that allows sub-minimum wage for PWD (Gander, 2018).</td>
</tr>
</tbody>
</table>

**Figure 1. Comparison of Disability Rights Laws and Supreme Court decisions to the everyday reality for Persons with Disabilities (PWD).**
The Costs

An inclusive community, with regards to disabilities of its residents and visitors, has typically been measured by the width of sidewalks and doors, the presence of ramps and elevators, and educational opportunities. Those on the autism spectrum, however, are more likely to be socially isolated, unemployed, and living in poverty than any other disability demographic (Heasley, 2013; Singh, 2015). The Centers for Disease Control and Prevention (CDC) recently reported the prevalence of autism is now closer to 1 out of 59 (Autism Speaks, 2018); whereas, the 2016 National Survey of Children’s Health estimated that number as closer to 1 out of 40 (Nedelman, 2018).\(^5\) To clarify what autism spectrum disorder is: “autism include(s) delayed learning of language; difficulty making eye contact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills’ and sensory sensitivities”\(^6\) (Autism Society, 2016). The saying within the autism community and its related fields of study is “Once you’ve met a person with autism. You have met just one person with autism” because any one individual can exhibit any one – or combination -- of those challenges to any degree.

It is estimated that the United States spends a mean annual cost of $236 billion a year on autism, contingent upon 40 percent of the 3.5 million Americans with autism\(^7\) also having intellectual disabilities (ID) (Buescher, Cidav, Knapp and Mandell, 2014) as shown in Table 1. Table 2 and Table 3 show that if the comorbidity rate for autism and ID across all age groups is

\(^5\) CDC numbers are based on data from 11 communities monitored in America. The National Survey of Children’s Health is conducted by the Census Bureau and surveys parents of more than 50,000 children under 17 years old (Nedelman, 2018).

\(^6\) Autism in this text includes classic autism, Asperger’s, and Pervasive Developmental Disorder-Not Otherwise Specified.

\(^7\) Buescher et al.’s autism population numbers are based on the CDC estimated prevalence of 1.1% of Americans diagnosed with autism spectrum disorders.
60%, then the spending, primarily from public funds, is $262 billion. The numbers include residential care (accommodations), special education, medical and non-medical services, employment support, and productivity loss of parents and adults with autism for which the authors state are “likely underestimated” because of a lack of research on the subject. According to Buescher, Cidav, Knapp, and Mandell (2014) estimated lifetime expenditures are between $1.4 and $2.4 million per person based on an assumed life expectancy of 67 years. The variation in expenditures accounts for those with and without intellectual disabilities. The Buescher et al. study was performed by updating and supplementing previous studies.

Table 1. U.S. population with autism spectrum disorder and the mean annual cost based on 40-60 ratio with and without intellectual disabilities.

<table>
<thead>
<tr>
<th>Age Range</th>
<th>No. of Individuals</th>
<th>Mean Annual Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with intellectual disability</td>
<td>0-5</td>
<td>115,909</td>
</tr>
<tr>
<td></td>
<td>6-17</td>
<td>227,727</td>
</tr>
<tr>
<td></td>
<td>≥ 18</td>
<td>1,072,727</td>
</tr>
<tr>
<td>Individuals without intellectual disability</td>
<td>0-5</td>
<td>173,864</td>
</tr>
<tr>
<td></td>
<td>6-17</td>
<td>341,591</td>
</tr>
<tr>
<td></td>
<td>≥ 18</td>
<td>1,609,091</td>
</tr>
</tbody>
</table>


---

8 In the absence of family or individual wealth, residential care is paid by Medicaid, and the individual receives $40 per month from Social Security Insurance for incidentals, clothing, etc.

9 Donald Gray Triplett, the first person (Case 1) diagnosed with classic autism – the severe form of autism – is 83 years old, a graduate of Millsap’s College, retired bank teller and world traveler (Pallardy, 2019).
Table 2. Mean costs per year per capita per child (0-17 years old) with and without intellectual disability by category in 2011.

<table>
<thead>
<tr>
<th>Component</th>
<th>Children with ID by age</th>
<th>Children without ID by age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-5</td>
<td>6-17</td>
</tr>
<tr>
<td>Accommodation or residential care (Medicaid funded)</td>
<td>1,903</td>
<td>9,516</td>
</tr>
<tr>
<td>Respite Care</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Special Education</td>
<td>62,290</td>
<td>27,961</td>
</tr>
<tr>
<td>Employment Support</td>
<td>0a</td>
<td>0a</td>
</tr>
<tr>
<td>Medical Services</td>
<td>12,933</td>
<td>18,106</td>
</tr>
<tr>
<td>Non-medical Services</td>
<td>11,387</td>
<td>11,387</td>
</tr>
<tr>
<td>Productivity loss (parents)</td>
<td>18,720</td>
<td>18,720</td>
</tr>
<tr>
<td>Voluntary Organization help</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Benefits</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total costs</td>
<td>107,863</td>
<td>85,690</td>
</tr>
</tbody>
</table>

Abbreviations: ID, intellectual disability; NA, not applicable

a Assumed to be zero.

b Calculated for children 6 to 21 years of age.

Note. From Buescher, Cidav, Knapp, and Mandell, 2014

Table 3. Mean annual costs per capita for U.S. adults, 18 years of age and older, in 2011 with and without intellectual disability by category.

<table>
<thead>
<tr>
<th>Cost category</th>
<th>With ID</th>
<th>Without ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation (Residential care)</td>
<td>36,161</td>
<td>18,080</td>
</tr>
<tr>
<td>Education</td>
<td>0a</td>
<td>0a</td>
</tr>
<tr>
<td>Employment support</td>
<td>705</td>
<td>352</td>
</tr>
<tr>
<td>Medical Services</td>
<td>27,159</td>
<td>13,580</td>
</tr>
<tr>
<td>Non-medical Services</td>
<td>11,387</td>
<td>5,693</td>
</tr>
<tr>
<td>Productivity loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual with ASD</td>
<td>10,718</td>
<td>10,718</td>
</tr>
<tr>
<td>Parents</td>
<td>1,896</td>
<td>1,896</td>
</tr>
<tr>
<td>Family expenses</td>
<td>0a</td>
<td>0a</td>
</tr>
<tr>
<td>Total Costs</td>
<td>88,026</td>
<td>50,319</td>
</tr>
</tbody>
</table>

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability.
a No data available.

Kitchener, Ng, Miller, and Harrington (2006) found that community care versus long-term residential care resulted in a national average expenditure savings of $44,000 per individual in 2002. These numbers are not presented here to show autism as “a burden on society,” but to point out the cost of “normalizing” a segment of society. “Awareness” is not the same as “acceptance,” and “Autism Awareness Month” can be as offensive to self-advocates as “Black History Month” is to many in the African American community. Integration is not the same as inclusion. Extinguishing “abnormal” behaviors, such as rocking or lining up toys, through long-term Applied Behavior Analysis is costlier than accepting that it as a part of that autistic person’s being. Institutional care is costlier than acceptance, supports, and accommodations. With an expected half million children with autism aging out of school services over the next decade, community developers must redefine what an inclusive community is because the cost of the medical and charity models of care are unsustainable.

**Employment, Isolation, and Poverty**

According to the Bureau of Labor Statistics (BLS), the overall unemployment rate across all disabilities in 2016 was 10.5 percent with only 20 percent labor force participation compared to 4.6 percent unemployment rate for persons without a disability (BLS, 2017). Young adults with autism in their twenties, however, were far less likely to be employed than their counterparts with other disabilities (Figure 2) (Roux, Shattuck, Rast, Rava, & Anderson, 2015). The 35% of 18-year-olds with autism who attend college fare worse finding employment than those with autism who did not attend college (Pesce, 2017). (Pesce’s article focused on a nonprofit organization in New York City, called Integrate, that provides job search, and employment supports to autistic adults and to bridge gaps with employers.) According to this study, 85% of college-educated autistic adults were unemployed when the national
unemployment rate was 4.5%. Those autistic adults who did find employment were more likely to be part-time and minimum wage employees.

![Bar chart showing employment rates](image_url)

Figure 2. Comparison of employment rates of young adults with disabilities. Note. From Roux, Shattuck, Rast, Rava & Anderson, 2015.

The 2016 Census estimated that 27 percent of working-age adults with disabilities in America live below the poverty level, compared to 11 percent of those without disabilities (U.S. Census Bureau, 2016). According to a Drexel University’s School of Public Health report, though, while those with autism who used vocational rehabilitation services received jobs at a comparable rate to those with other disabilities, the wages, hours worked, and job types for those with autism were low, tending to put them at greater risk of poverty. In fact, 80 percent of those with autism who left vocational rehabilitation with a job worked part-time when compared to 19 percent for the rest of the population (Otto, 2016).

Paul Shattuck, one of the investigators in the Drexel study, observed that the shift of the American economy from manufacturing jobs in the 1970s to service sector jobs has had a significant impact. “(T)hose types of jobs, which require lots of social interaction, are exactly the
types of jobs that people with autism have difficulty with,” Shattuck stated (Otto, 2016). He added that “Although the core of the disability is an inability to relate easily to other people, the majority of people on the spectrum do have some amount of social appetite.” Shattuck’s research, the National Longitudinal Transitional Study-2 looked at a sampling of students from 13 to 16 years old in special education during high school and as they transitioned to adulthood. They found that one in four young people on the spectrum was completely isolated. According to the research, 28 percent had no social contact at all, 40 percent never saw friends and half were not receiving phone calls or being invited to activities (Heasley, 2013).

Leading community development researchers have determined that social capital is a predictor of financial capital (Flora and Flora, 2013; Pigg, Gasteyer, Martin, Apaliyah and Keating, 2015; Putnam, 2000). The Department For International Development points to social exclusion as a key driver of poverty for persons with disabilities.

“Exclusion is frequently more subtle and unintentional, for example when disabled people are excluded from services, markets and political participation through a lack of awareness of their needs or by social attitudes…. It hurts them materially – making them poor in terms of income, health or education by causing them to be denied access to resources, markets and public services. It can also hurt them emotionally, by shutting them out of the life of their community. Socially excluded people are often denied the opportunities available to others to increase their income and escape from poverty by their own efforts. So, even though the economy may grow and general income levels may rise, excluded people are likely to be left behind, and make up an increasing proportion of those
who remain in poverty. Poverty reduction policies often fail to reach them unless they are specifically designed to do so.” (DFID, 2005)

**Key Concepts**

It is necessary to define key terms used in this thesis: disability, neurodiversity, and community. “Disability,” as addressed here, specifically deals with the social construct and barriers that community developers can affect. “Neurodiversity” moves away from the deficit model to one that welcomes learning and neurological differences as “normal variations of the human genome” (Disabled World, 2017). “Community” takes a micro- and macro-level approach to discover what is working, and how we can improve outcomes for those on the spectrum.

**Disability: The Label and the Stigma**

Social and economic justice for persons with disabilities require that community developers unpack some of the ugly, historical baggage that has led the nation to where it is today with this demographic (Hustedde, 2015). Over the past several years, various groups of people have taken to the streets demanding social justice and equity. Organizers list the marginalized groups on television and radio talk shows…people of color, women, the poor, Indigenous peoples, immigrants, LGBTQ. Rarely are the “disabled” included in their litany. It is important to expand upon Alinsky’s (1971) concept of “double segregation” – based on economy and race in his work – here. The more non-White, male, cis-gendered, abled adjectives that identify a person, the more segregated that person is (Williams, 2019). The lexical units of the word “disability” (dis- meaning lacking) and its synonyms (incapacity, invalid, inability, ineffective) begin at deficiency within the person or community. “When disability is equated with dependency, disability is stigmatized. Citizens with disabilities are labeled inferior citizens.
When disability is understood as dependency, disability is posited in direct contrast to American ideals of independence and autonomy” (Nielsen, 2012, p. xiii).10

Indiana led the way with the first sterilization law in 1907, before Nazi Germany. The United States also was the first to use “intelligence quotients” (IQ) to stratify, and, ultimately, discriminate, the human race based on social, gender, race and ability, even though IQ developer Alfred Binet did not consider IQ numbers to be an exact representation of human intelligence (Friedlander, 1995). In 1917, psychologist Robert M. Yerkes and his team administered the first mass-produced intelligence test to 1.75 million American Army soldiers.

Although many of the tests were given to recent immigrants unfamiliar with the English language and American culture, the psychologists concluded that the results revealed not cultural differences but hereditary intelligence. These mass tests served as a model for others; for example, one of Yerkes’s followers, the Princeton psychologist Carl C. Brigham, later served as secretary of the College Entrance Examination Board and developed the Scholastic Aptitude Test. (Friedlander, 1995, p. 5).

In 2012, the neuroscience journal Neuron published a study on 100,000 participants demonstrating that there may be at least three components of intelligence: short-term memory, reasoning and verbal recall (Mann, 2012). As autism advocate Chantal Sicile-Kira (2011) stated, “For a child to perform to their ability on a standard IQ test such as the WISC-IV and the Stanford-Binet, they must be able to quickly respond to verbal questions and have well-

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10 Nielsen expertly documents the marginalization of persons with disabilities since early colonialism in her book, A Disability of History of the United States (2012) and will not be summarized here.
developed motor skills. However, these are areas that are difficult for those with autism. In effect, these IQ tests do not tap the true cognitive ability of many children on the autistic spectrum, but rather tell us more about their communication and motor difficulties.” The association of language – particularly spoken language – with intelligence contributed to the derogatory term “deaf and dumb.” When Son was diagnosed with autism, upwards of 90 percent of people with autism had a comorbid diagnosis of intellectual disability, and roughly 50 percent of those with autism never spoke. Now, with more proper evaluations, the number of those with comorbid intellectual disabilities diagnosis is 32 percent and, thanks to technology and communication devices the number of individuals with autism who are “nonverbal” has dropped to 25 percent (Autism Speaks, 2017a). Although this researcher’s son is “nonverbal,” he can quickly and clearly use those colorful, four-letter words in context to make his point that he does not want to do something or what he thinks of people who do not know his favorite television characters. He is also quick to tell people talking about him in front of him that he is not stupid and that he is not a baby. Timmy, who uses an assistive communication device, said it best: “I am smart…. People act like I am not hearing when they talk about me…. I am not deaf. I am not slow or cognitively stupid. I hear what you say about me. It is hurtful so please don’t talk about me in front of me” (SeattleChildrens, 2014). Timmy later interjected into the panel discussion that “his brain doesn’t prune anything,” demonstrating that he reads journal articles. Susan J. Peters (2009), referencing Yeo, and speaking specifically to the education of persons with disabilities, stated that, “…impairment does not inevitably lead to disability and poverty. It is at the point of discrimination that the cycle could be broken. If disabled people are denied education opportunities, then it is the lack of education and not their disabilities that limit them.”
Over the past decade, there have been some incidents when parents have killed their children in murder-suicide acts (Rodriguez and Fernandez, 2012; Digital Staff, 2013; WSAZ, 2017; Stafford, 2015). The media frames the conversation, with the aid of leading autism ableists, such that an autism diagnosis is hopeless, individuals and their families “suffer from autism,” that these parents who murder their children are sympathetic victims, and those parents who do cope are somehow “saints” or “chosen by God.” The onus is on the individual and the family, not the lack of resources, or support and accommodations within the community.

(Parents of autistics often take note of responses when their child has a meltdown in public: it is blamed on their parenting abilities, not on the environment, a schedule change, or a breakdown in communication.)

Then, there are the adults. In February 2016, Mesa, Arizona police officers responded to the home of Danielle Jacobs, a 24-year-old woman with Asperger’s, a milder form of autism (Ellis, 2016). The initial call to police indicated that the woman was threatening to kill herself. When Jacobs lunged at the officers with a large kitchen knife, both officers fired their weapons, killing Jacobs. Jacobs had shared her life on social media and at one point was upset that vocational rehabilitation had denied her access to a college education. The Mesa police department said they were unaware of Jacobs’ diagnosis and challenges. More recently, 18-year-old Ricardo “Ricky” Hayes was shot by a Chicago police officer on August 13, 2017 (AlJazeera, 2018). His caregiver had reported him missing, along with information about his disabilities. Hayes was unarmed.

Following the Sandy Hook school massacre in 2012, the media frenzy without confirmation at the time swiftly connected Asperger’s with mass violence, and not without consequence. [Documents later released to the media confirmed an autism diagnosis (CBS/AP,
Blogger NeuroDivergent K wrote at the time: “Now every time someone does something violent, they are speculated to be autistic. And, just as some killers who were speculated to have crappy home lives actually did, just as the Columbine killers actually were bullied, there is a possibility that there will be a mass shooter who is Autistic. But that does not make all of us dangerous.... Passing the blame down to another group without power hurts people” (Wagner, 2012). Also, as The Autism Society wrote at the time, “To imply or suggest that some linkage exists is wrong and is harmful to more than 1.5 million law abiding, non-violent and wonderful individuals who live with autism each day” (Wagner, 2012).

Dylann Roof and the massacre at the Emanuel A.M.E. Church followed three years later on June 17, 2015. When Roof discovered that his attorneys planned to use autism as a defense for mitigating factors, Roof moved to represent himself (which the judge granted), stating, “If people think I have autism, it discredits the reason why I did the crime. Once you've got that label, there is no point in living anyway” (Tripp, 2017). This perception by many is confirmed by John Elder Robison, an autistic adult and an expert in the field who has worked with the World Health Organization and the U.S. government, author, a parent of an autistic adult son, and author of the defense team’s Exhibit 1 (2016) in the Roof case. A psychologist hired by the defense team diagnosed Roof with autism in the summer of 2016. According to the report, Roof told Robison, “The state’s psychiatrist said there’s nothing wrong with me. I am just a sociopath.” Robison continued, “In my experience, it is common for people to deny autism diagnoses whether out of shame and embarrassment or due to lack of insight and rigid thinking.” (Parents often may not disclose an autism spectrum diagnosis to their child’s school for fear of stigma or, before the DSM-5 when Asperger’s and pervasive developmental disorder—not otherwise specified were separate diagnoses from autism, may have requested a lower-
functioning diagnosis to tap into services for which the student may not otherwise qualified.)

Citing several other studies, Gillespie-Lynch, Kapp, Brooks, Pickens, and Schwartzman stated, that “stigma toward behaviors associated with autism is reduced when people are made aware that the people exhibiting the behaviors have a diagnosis by decreasing perceptions of personal responsibility for atypical actions. Indeed, autistic people with fewer symptoms (who appear more ‘normal’) report higher levels of stigma directed toward them than their more severely affected peers, possibly because non-autistic people misinterpret them as intentionally deviant” (2017, p. 2).

For his report, Robison performed many interviews, including with attorneys, family members, including Dylann Roof himself, reviewed jail video of interactions between Roof and his family, Roof’s confession, school, and medical records, Roof’s journals, website, and personal pictures. The following notes from Robison’s report are included here not as an excuse for the murders, but points that should be of significance for community developers.

• “Autism is painful when our communication disabilities make it hard to make friends or make us targets for ridicule and bullying” (p. 2), later noting that “The autistic person does not know his conversational behavior is rude, or that he is interrupting, because of his disability” (p. 8). (The very nature of autism creates a lack of social capital which, in this case, produced a vacuum ultimately filled by online hate.)

• When Dylann was around 12 years old and for the next four years, he and his mother, who relied on public assistance, moved four times. He quit school at 16 (pp. 10-11). All of which, presumably, reduced the social capital among what peers he had had during the earlier years. Change can also exacerbate autistic symptoms.
• A month before the murders, fed up with Dylann’s isolation and a lack of job, his parents told him he could no longer live with them unless he worked and paid rent (as would be expected of “typical” adults) (p. 8).

• Dylann’s conversational style – an autism identifier -- would have been off-putting to those outside the family. Dylann was arrested at a mall for trespassing. His grandparents related the story to Robison: “The news media reported that Dylann was going from store to store in the mall, saying weird things…. But maybe that was just Dylann, trying to get a job and not knowing what to do” (p. 8). As Robison explained, “A person who can’t read others is at a particular disadvantage when trying to talk to a stranger. When he’s trying to do something unfamiliar, he is very likely to say or do the wrong thing, and fail. That may well have happened with Mr. Roof at the mall. Yet the parental response – that their son was an adult and had to engage the adult world – was typical. The tragedy here is that no one recognized a very real disability in young Mr. Roof. He never received any supports or counseling, and he became increasingly disconnected as he grew older” (p. 8).

Robison ultimately argued that the more intelligent individuals on the autism spectrum are more hurt by isolation than those with cognitive challenges who may not realize their isolation (p. 25). Perhaps. But Robison’s contention is questionable if “cognitive challenges” are based on traditional “intelligence” and verbal language skills, which perpetuate a stereotype, versus scientific research, and dismisses Shattuck’s view stated earlier in this study that most autistics do want some form of socialization. A counterfactual is that without socialization for any individual with autism, the symptoms of autism can be markedly worse. Andrew D’Eri is an example of how socialization can have a positive impact on a person with autism. Andrew’s father, John, described Andrew as “…you don’t care much about what is going on around you.
You know, you’re happy alone. You like routine. And, you know, interaction with people is kind of optional or sometimes it’s ‘I just don’t wanna.’” Andrew also has a limited diet, which is typical of autistics. John and his neurotypical son, Tom, started a social enterprise, Rising Tide Car Wash, for Andrew and other autistics in Parkland, Florida. According to John, two weeks after Andrew started his job at Rising Tide, he was willing to try new food, showed empathy, and teamwork (TEDx Talks, 2014).

**Neurodiversity: Reframing the discussion**

In the late 1990s, sociologist Judy Singer coined the term “neurodiversity” (Disabled World, 2017). Singer, wishing to move away from the traditional deficit model, has argued that learning and neurological differences “are a result of normal variations in the human genome.” Followers of Singer’s school of thought may prefer the term “autistic” versus the People First language -- “a person with autism” -- because the former believes that “to take away the autism is to take away the person. As such, neurodiversity activists reject the idea that autism should be cured, advocating instead for celebrating autistic forms of communication and self-expression, and for promoting support systems that allow people with autism to live as someone with autism” (Disabled World, 2017). Callahan (2018) states that individuals with autism prefer the term “autistic person” because it conveys empowerment; whereas, parents and some professionals prefer the person-first phrase. Therefore, the term “autistic” is used throughout this study in alliance with self-advocates.

The neurodiversity movement does not ignore the challenges that come with autism. Some parents of lower-functioning autistics – those with classic autism who heavily depend on supports and services – have pushed back against the neurodiversity movement and shows such as *The Good Doctor*, suggesting that self-advocates are opposed to medical research and presents
autism as roses and rainbows. However, that is not the case. Gillespie-Lynch et al. (2017), referencing a number of other studies, stated “…self-advocates in the neurodiversity movement vary widely in their support needs; they often reject functioning labels as hierarchizing development in relation to an illusory ideal of “normal” that some autistic people are more (i.e., high-functioning) or less (i.e., low-functioning) close to while obscuring contextual variations in abilities, with potentially adverse consequences in terms of autistic individuals obtaining needed supports” (p. 3).

Lanza and Roof were clearly on the higher functioning end of the autism spectrum; however, the stigma associated with a disability versus the acceptance of autism as neurodiversity in need of varying supports certainly hindered Roof from getting the supports he needed, it appears. Additionally, those on the lower functioning end of the spectrum may have resources available to them, such as adult day habilitation programs or even institutionalization, but those on the higher end of the spectrum may fall through the cracks.

Community

Flora and Flora (2013) summarize various sociological definitions of community: “location, social system and common identity” (p. 9), condensing primarily to communities of place and communities of interest. Pigg and Bradshaw (2003, p. 386) note that “Rural communities are linked in increasingly specialized networks, the economy is in flux, the community of place is being complemented by communities of interest….” Bhattacharyya takes to task the idea of a simple community of place in that “it obscures another understanding of the term that transcends all connections of place, such as Durkheim’s organic solidarity and Tonnies’s Gesellschaft, a solidarity based upon shared interests or circumstances. It is this quality that is invoked for such bodies as the Jewish community, the Christian community, the
community of Islam (the Umma), the Black community, the medical community, and, at an earlier time, trades union. In this sense of community, place is incidental, not integral to its definition…” (2004, p. 11). And so is the case with the autism community. Considering one out of every 40 to 59 people are now diagnosed with autism, there may be several or many autistic people in a community. The internet with its various means of connecting transcend place to a community of “shared interests or circumstances,” using Bhattacharyya’s words. Neither definition (community of place or community of shared interest) can be dismissed when discussing the autism community since local environment, and cultural norms have a significant impact on a local autism community’s outcomes, but the resources found in the community of interest can transcend those geographical boundaries to have positive outcomes in the local space.

**Research Question**

According to Emery and Flora’s Community Capitals Framework (2006, p. 23), they argue that “as one capital is increased, it is easier for increases, instead of declines, in the other community capitals to occur,” called “spiraling-up,” and contend that social capital is “the best entry point to spiraling-up,” and that “infusions of financial capital or built capital is often not cumulative.” Although social capital – whether bridging or bonding (Putnam, 2000; Flora and Flora, 2013) – is necessary for inclusion for the autism community, once the individual graduates or turns 22 that social capital gained in the education system can dissipate as classmates go on with their next phase of life. It can be argued that the “social capital” found in the charity and paternalistic models, such as day habilitation programs, sheltered workshops that pay a sub-minimum wage, or “volunteering,” do not result in the same spiraling-up that is found in the typical community. Social constructs, barriers, and attitudes in the medical/charity/paternalistic
models create a disability for individuals to overcome versus intentional design that promotes inclusion and sustainability.

The research question for this study is: What specific types of accommodations, modifications, resources, and supports are communities providing for autistic adults that are having positive outcomes?
CHAPTER 2. LITERATURE REVIEW

Much of the literature that is available regarding individuals with disabilities in communities is in the fields of disabilities studies, education, psychology, and vocational rehabilitation. A growing body of work in entrepreneurship and small business ownership has begun since 1990 with the self-determination movement, along with literature following the ratification of the United Nations’ Convention on the Rights of Persons with Disabilities. Single quantitative studies can form an incomplete picture of what is happening within states.

The Hechinger Report (Butrymowicz and Mader, 2017) found that Arkansas had the highest percentage of special education students graduating on time, 17 percentage points higher than the national average. The reporters did perform interviews with 45 parents and students and 50 experts in the field from 34 states to highlight systemic issues. The on-time graduation rates should be viewed with caution, however. Based on this researcher’s experience and observations, if parents are not aware that their children can be educated until they are 22, school personnel will not volunteer that information. Therefore, a parent population that is less educated would be less likely to know their children’s educational rights. Compare Arkansas’ position on The Hechinger Report to its’ 49th position (out of 51) on the United Cerebral Palsy’s report ranking states according to the organization’s inclusive criteria (Bragdon, 2016). Vocational rehabilitation numbers may not take into account those who are not accepted into rehabilitation programs because they would skew the data downward if they do not succeed, those unable to score sufficiently on intake exams or the individual who is unable to attend programs away from home because those receiving Medicaid Home and Community-Based Services must be independent enough to live without their support staff in dormitory settings. Quantitative data does not take into account that more than a decade ago, a representative from the state
Vocational Rehabilitation program spoke at a state disabilities conference. In his speech, he told attendees to “wait their turn” for employment as they would be needed when Baby Boomers retire. No other minority population would have taken that comment in absolute submission. In 2016, Arkansas Department of Human Services (DHS) changed the hours individuals with physical disabilities and the elderly who needed in-home care under ARChoices – a Medicaid waiver to institutional care program -- from hours recommended by a nurse to a computer algorithm, which cut hours of community care to that population. As a lawsuit has wound its’ way through the state court system, DHS later threatened to end the entire ARChoices program (Hardy, 2018).

If disability service organizations are tied to government bureaucracies through Medicaid and Medicare funding, self-determination may be secondary to the organizations’ funding stream. The battle for inclusion as adults become no different than what parents faced in the educational system. As des Jardins wrote, “It doesn’t matter how friendly, how nice a bureaucrat is – if he does not give you the services your child is entitled to, he is not your friend. Many bureaucrats use friendliness and flattery as a form of intimidation, another way to keep parents quiet while they go about their do-nothing routine. Many parents fall for the ‘sweetness and light’ routine” (1993, p. 111), and, continuing, “Cooperation with bureaucrats will often mean cooperating in their adherence to the status quo, cooperating in their resistance to new ideas, and cooperating in closing the door to changing the system. It might also mean cooperating and bringing about negative change, in removing protections and safeguards in rules and regulations, in removing services…” (p. 121). Des Jardins’ school of thought is similar to that of Myles Horton, co-founder of the Highlander Folk School, who believed that systems change can only occur from outside the system – regardless of the system – because those inside the system co-
opted the ideals, “made it more palatable and justified it” (Bell, Gaventa and Peters, 1990, p. 200). Although Hiranandani, Kumar and Sonpal’s 2014 article on inclusion studied India, it is also relatable to America where, especially in functionalist states and communities, “disability policy still remains deeply embedded in the charity/welfarist and medical approaches” (p. 153). The medical approach is evident when adults with intellectual disabilities who receive government support must endure annual IQ evaluations, even though according to the psychology field, IQs do not change. The charity/paternalistic model is represented by “asset-based” approaches to community development that consider the housing provided to a typical person, or the positive emotions the person with disabilities brings to an abled person, both representations of “inspirational porn” centering the abled person versus building on the individual’s true strengths, such as the ability to pay attention to detail or the ability to stay on task. Those organizations providing early childhood services may not be inclined to provide appropriate intervention services if they will also, in the future, provide adult support services. Nisbet, Hagner, Antal, Fox, and LaPointe (2006) stated, referencing earlier studies,

During the 1970s and 1980s, states began to develop comprehensive systems of community services for children with disabilities, largely in response to court deinstitutionalization orders. For the most part, neither the recipients of services nor the communities in which they lived or were placed were involved in the design of those systems. Many of the resulting programs included congregate structures such as group homes and sheltered workshops that resembled smaller versions of their institutional predecessors. The system as a whole continued to operate within the centuries-old medical model of disability in which problems resulting from disability were viewed as individual rather than social problems,
assistance to individuals with disabilities was under the control of professionals. Adherence to the medical model was further strengthened in the 1990s, as states placed their developmental and mental health services under the federal Medicaid program in order to obtain reimbursement to offset rising costs. (T)he fundamental organization of the service system and its relationship to the community has remained virtually unchanged for 30 years. The design of community services remains firmly in the hands of state and federal Medicaid officials and human service agencies. (pp. 71, 73)

**Survey of Literature**

A Boolean search statement uses database logic to tell the search engine what to include and exclude from the search (MIT Libraries, n.d.). The Boolean operators “AND,” “OR” and “NOT,” allow a researcher to broaden or narrow a literature search, which makes the review more manageable and focuses the search on those articles that apply to this research. Operators “AND” and “OR” tell the search engine what to include, whereas “NOT” indicates what to omit from the search. The logic model in Figure 3 can help visualize the Boolean search statement process (Maddix and Anderson, 2017).
“Community development OR economic development” remained the same throughout the search statement revisions. The intent was to search for “community development OR economic development” plus (AND) “disabilities OR autism OR autistic,” but exclude keywords that did not fit this thesis’ study parameters. Hence, the initial Boolean search was (community development OR economic development) AND (disabilities OR autism OR autistic) NOT (health OR rehabilitation OR “race, gender, sexual orientation, religion or disability”) which resulted in 5,672 items, including 823 peer-reviewed articles. The exclusionary terms were selected to omit specialty fields of health, rehabilitation, and the stock discrimination disclaimer. Including “education” and “school” to the exclusionary list reduced the number to 2,918 results of which 196 were peer-reviewed articles. Removing disabilities and including only “autistic” or “autism” along with “community development OR economic development” at this point returned “0” results, indicating that the word autism alone had not been studied and published in connection with community or economic development in the available database. The final
Boolean was: (community development OR economic development) AND (disabilities OR autism OR autistic) NOT (health OR rehabilitation OR education OR school OR “race, gender, sexual orientation, religion or disability”). Further refining the topics included excluding subjects under education, international relations, and history and archeology so that the final results were 166 peer-reviewed journals of 2,888 total items. Upon closer inspection of individual articles, those that did not solely address persons with disabilities, those that considered only mobility impairments or physical accessibility, those with aging and disabilities -- which would indicate acquired or physical disabilities -- those covering medical interventions, international articles that passed through earlier filters, as well as editorials and proclamations were excluded. The eight articles in Table 4 remained. Five of those articles were from a special issue of Community Development, the journal for the Community Development Society, and covered topics such as housing, transportation or inclusion in places of worship. (It is important to note that these results were strictly from the Iowa State University database; whereas, the same search through a University Centers for Excellence in Developmental Disabilities – of which Iowa State University is not – may result in more applicable studies.) The common theme throughout the studies in the issue was initiatives led from the overall communities’ desires to change but does not examine functionalist communities that operate on hierarchal structures. None of the studies used participant observation or participatory action research methods.
Table 4. Survey of Literature.

<table>
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<th>Method</th>
<th>Key Relationships</th>
<th>Findings</th>
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<td>Ipsen, C., Seekins, T.,</td>
<td>Used Rural: RTC’s Guidebook for Citizen Involvement and Expanded Businesses in Rural</td>
<td>Case studies w/interviews</td>
<td>A sponsoring disability agency, co-sponsoring economic or business dev’t agency and two PWD to serve as team leaders, and study team members.</td>
<td>79 new businesses with 192 jobs created (66 businesses still going two years later) in Utah. $694,000 in agency grants leveraged nearly $2 million in personal investments and loans.</td>
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<td>Arnold, N., &amp; Kraync, K.</td>
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<tr>
<td>Guillory, J.D., Everson,</td>
<td>33-month Coalition-building project with PWD specifically targeted for inclusion in</td>
<td>Case Studies</td>
<td>Committees, agencies, public systems and PWD in each community targeted “needs.”</td>
<td>One community was still in the storming stage, but three others made significant progress. One community’s PWD went from interest in process to outcomes.</td>
</tr>
<tr>
<td>Sept.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Nisbet, J., Hagner, D.,</td>
<td>36-month grant project bringing service industry, city and PWD together to design</td>
<td>Empowerment evaluation</td>
<td>City and community attempting to move away from systems’ design to intentional inclusion of PWD, in a community-centered approach v person-centered.</td>
<td>Community-centered approach is possible. Made accessibility changes, including sports programs, information, and trade in skills. Community was small, and researchers hope for replicability.</td>
</tr>
</tbody>
</table>
Table 4. (continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Area Investigated</th>
<th>Method</th>
<th>Key Relationships</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evanson, T.A., Ustanko, L. &amp; Tyree, E. (2006).</td>
<td>Faith communities in Grand Forks, ND/East Grand Forks, MN</td>
<td>Surveys, pre- and post-assessments, community dialogue</td>
<td>Intentional design with Program Coordinator of the Arc as the lead spilling out to parish nurses and then congregations.</td>
<td>Collaboration and communication between PWD, congregations and service providers are essential with a diverse disabilities population and strong self-advocates.</td>
</tr>
<tr>
<td>Fernando, B. (2005, April-June).</td>
<td></td>
<td></td>
<td>Article giving examples of how technology can open job markets for individuals with disabilities.</td>
<td></td>
</tr>
<tr>
<td>Feinstein, C.S., Levine, R.M., Lemanowicz, J.A., Sedlak, W.C., Klein, J. &amp; Hagner, D. (2006).</td>
<td>Interviewees lived in 9 states and were part of the National Own Your Own Home Alliance begun by the University of New Hampshire. 23 state coalitions helped 900 PWD become homeowners.</td>
<td>129 In-depth interviews with successful, pending and unsuccessful homeowners</td>
<td>Financial institutions, community housing agencies, and organizations for PWD.</td>
<td>PWD who own their own home has more self-determination and connectedness to the community.</td>
</tr>
<tr>
<td>Carmen, S. (2015).</td>
<td></td>
<td></td>
<td>Short article about housing complex in Austin, TX that hosted game night.</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 3. METHODOLOGY

The operationalization of concept for this study was to develop a survey based on Appreciative Inquiry (AI), distribute it to 15 disabilities organizations or social media sites with a combined 3.6 million followers, which, in turn, would build the snowball sampling. Qualtrics software at Iowa State University was used to distribute and collect the responses. This study deviated from historical uses of Appreciative Inquiry since open response survey questions were used instead of traditional interviews or focus groups, and all steps relied on digitalization. Additionally, AI is also most often used in an organization development process, but it is used here in conjunction with the Community Capitals Framework as discussed later in the analytical framework section of this chapter.

Appreciative Inquiry

Proponents of asset-based community development are critical of deficit-based models because of the psychological impact on the community and the self-sustaining payoffs for nonprofits, institutions, and governmental agencies (Bushe, 2007; Pigg and Bradshaw, 2003; Kretzmann and McKnight, 1996). Although AI is – as the name indicates – about what is positive about an organization or community, it is also intended to be generative. As Bushe (2007) explained, “It is the quest for new ideas, images, theories and models that liberate our collective aspirations, alter the social construction of reality and, in the process, make available decisions and actions that weren’t available or didn’t occur to us before. When successful, AI generates spontaneous, unsupervised, individual, group and organizational action toward a better future.” By using an Appreciative Inquiry approach to this study, families in rural Arkansas may discover new ideas for them from families in rural South Dakota, and while this study surveys
autistic adults, it is they and their families who have the lived experiences that can set a different course for others.

Whitney and Trosten-Bloom discovered that AI works because it generates six essential conditions, identified as Six Freedoms, which, in this researcher’s opinion, are critical to changing the dialogue about autism and developing autism-friendly sustainable communities. They call these conditions Six Freedoms.

1. Free to be known in relationship.
2. Free to be heard.
3. Freedom to dream in community.
4. Free to choose to contribute.
5. Free to act with support.
6. Free to be positive. (Cooperrider, Whitney and Stavros, 2008, 27-29)

This study used the Discovery and Dream phases of Appreciative Inquiry in Figure 4 to discover what modifications, accommodations, resources, and support communities are providing that have positive outcomes for autistics. It allows autistics and their families to dream about what communities should do in the future to accommodate autistics, help them feel safe in the community, and a respected member. This study’s research focuses primarily on the Discovery and Dream phases of AI. However, these findings and further studies can be used to develop potential provocative propositions in the Design phase, which is critical to the sustainability of the Discovery and Dream phases. Any potential provocative propositions in this study would be limited due to the lack of dialogue between key stakeholders needed for this phase. The Destiny phase is not intended to be a one-size-fits-all response, but an opportunity.
for others to self-organize and share ideas of initiating change around AI versus focusing on a deficit-based model.

Figure 4. *The four phases of Appreciative Inquiry. Note. From Cooperrider, Whitney, and Stavros.*

**Surveys**

Cooperrider, Whitney, and Stavros note that after deciding stakeholders, an interview guide is developed, which is used typically in focus groups, interviews, and participant observations. As of the publication of the second edition of the *Appreciative Inquiry Handbook* in 2008, when writing about discussions with personnel at AMX, a telecommunications company, the authors note that “putting Appreciative Inquiry online is a very exciting venture that has yet to be done anywhere,” and considers an ongoing Appreciative Inquiry a possible “whole system transformation” (p. 393). AI summits now allow large organizations to use technology platforms to host summits, using the appreciative inquiry methodology, with
stakeholders around the world. Given the constraints of this study, the appreciative inquiry methodology was used in a much more rudimentary technology: the online survey. A survey with open-ended questions may not provide data that is as rich as personal interviews, or focus groups would, but, again, the study provides a starting point to change what inclusion looks like for autistic adults. Additionally, as Cooperrider, et al. note in their discussion of the proposed AMX online project, the purpose of this study and the chosen methods was “to accelerate the spread of innovations and good news storytelling” (p. 393).

Appreciative Inquiry will resonate with many self-advocates and pro-active families. Autism can be challenging, but we have a choice: We can look at only the deficits or we can choose to see the positive. John D’Eri (father) and Tom D’Eri (brother), instead of focusing on the negative, found that autism could be the “competitive advantage” to Rising Tide Car Wash in Florida that was designed for family member Andrew and to employ as many people on the spectrum as possible (TEDx Talks, 2014).

*Discovery and Dream: Survey Questions*

The appreciative interview guide “includes three types of questions: opening questions, topic questions and concluding questions (Cooperrider et al., 2008, pp. 106-108). According to the authors, an appreciative question consists of two parts:

- **Part A:** The question must evoke a real personal experience and narrative story that helps participants see and draw on the best learnings from the past.
- **Part B:** This part of the question allows the interview to go beyond the past to envision the best possibility of the future (p. 107).

Questioning individuals with autism can be challenging since one of the hallmarks of autism is an inability to answer interrogatives; therefore, the survey questions in Figure 5 were
open-ended directives. (For the complete survey, see Appendix A.) The survey statements, without the preface, were written on a 4.4 Flesch-Kincaid Grade Level for understandability. The overall survey was written on a 5.3 Flesch-Kincaid Grade Level. Qualtrics software, available through Iowa State University, was used to deliver, collect and initially store the surveys.

Some people and places value diversity more than others. This survey asks what these people and places are doing to support adults with autism. We want to know what an accessible community could look like in the future. Your responses can be about employment, a store, housing options, culture, or financial support. It is anything that makes you feel like a valued adult.

1. Tell me about an event or place where you have felt valued and welcomed. Describe more about your experiences.
2. Tell me what your community can do to help you feel valued and welcomed more consistently.
3. Tell me about a time when you were empowered to advocate for change. Tell me what the issue was. Your proposed change. Tell me how the issue was resolved.

Figure 5. Appreciative Inquiry Preface and Survey Questions.

Sample Population

Buescher et al. (2014) estimated that there are nearly 2.7 million autistic adults over the age of 18 in America. The sampling frame for this study were American households with an autistic adult 21 years and older with internet access and inclusive and equitable lifestyles. This research used an online survey to not only provide accessibility to a population that may face barriers to interpersonal relationships and verbal language communication but also to develop a larger number of sampling units. Online surveying clearly does not include those individuals with autism and their families who do not have access to internet service; however, theoretically, it is more inclusive than exclusive.

---

1 A case study approach was considered and rejected due to access to only communities that use the deficit-based medical and charity models, as well as the potential privacy and confidentiality issues with a vulnerable population.
Snowball sampling

Fifteen national disabilities organizations and social media pages with access to 3.6 million combined followers were chosen to create a snowball sampling. The organizations and social media pages included not only those whose focus was on specific autism-related issues but also several that focused on disability issues in general. The scope of the organizations and social media pages helped prevent identification of any one community or respondent household, as well as provide a diverse view of what is currently successful for adults with autism. Publication of the study advertisement on their organizational and social media sites would create a larger, unknown number of sampling units. Without snowball sampling, the respondents are otherwise a “hard-to-reach” cohort (Frankfort-Nachmias, Nachmias & DeWaard, 2015, p. 148) and would provide an insufficient number for data analysis. A letter of introduction and the Study Advertisement (Appendix B) was sent to each of the 15 organizations and social media pages through email or instant messaging if an email was not available. Publication of the advertisement and survey participation was without penalty or enticements and was to be shared with their affiliated organizations, members or followers.

Analysis was limited to the first 125 surveys completed by self-advocates, the first 125 surveys completed by family members, and the first 75 completed by “friends” for a total of 325 surveys to make the data manageable in the time constraints for this study. This study gives weight to responses from adults with autism first and their family members who may have guardianship or may be the individual’s “voice,” if they have communication challenges, and, then, friends. This hierarchy is reinforced with others’ findings (Migliore, Mank, Grossi & Rogan, 2006; Wituk, Pearson, Bomhoff, Hinde & Meissen, 2007; Andresen, Fitch, McClendon, & Meyers, 2000; Andresen, Vahle, & Lollar, 2001)
Vulnerable populations, the IRB, and social justice

When considering the historical abuses of vulnerable populations, including those with disabilities and the socio-economically disadvantaged, there are additional safeguards for those populations through the institutional review board process, which was necessary since 1) this research is intended for generalizability; and, 2) required interactions with human subjects. However, the intentional exclusion of persons with disabilities from research that could impact them is a social justice issue. It should be noted again here that a diagnosis of autism does not automatically equate to a co-morbid diagnosis of intellectual disability. The Institutional Review Board Guidebook reinforces that: “As a general rule, all adults, regardless of their diagnosis or condition, should be presumed competent to consent unless there is evidence of serious mental disability that would impair reasoning or judgment. Even those who do have a diagnosed mental disorder may be perfectly able to understand the matter of being a research volunteer, and quite capable of consenting to or refusing participation. Mental disability alone should not disqualify a person from consenting to participate in research; rather, there should be specific evidence of individuals' incapacity to understand and to make a choice before they are deemed unable to consent.” Additionally, the handbook states, “unlike research involving children, prisoners, and fetuses, however, no additional DHHS regulations specifically govern research involving persons who are cognitively impaired” (IRB Guidebook, 1993; Delano and Block, 2016). The handbook continues, “The recommendations of the National Commission for the Protection of Human Subjects resemble the recommendations made with respect to children.”

More recently, Annas and Glantz (1986) have argued that research should involve cognitively impaired subjects only where: (1) they comprise the only appropriate subject population; (2) the research question focuses on an issue unique to subjects in this population;
and (3) the research involves no more than minimal risk.” Using Annas and Glantz’s criteria, this research allows individuals with autism to give their voices to what works for them in their communities with no more than minimal risk. Prevailing thought, however, has changed since 1986 with the self-determination/People First and Nothing About Me, Without Me movements in the disabilities’ community. As Moira A. Keane stated, “Our current thinking on practices of inclusion and exclusion have moved beyond a ‘paternalistic’ or ‘protectionist’ stance to a more inclusive model where researchers are encouraged to include, with careful consideration, and risk mitigation and minimization, populations that are underserved, including socially and economically disadvantaged persons” (2016). There was concern that individuals who are under guardianship would participate in the study, even though research and case law has shown that guardianship is overused and abused (Morgan, 2015; Gurnon, 2016; National Council on Disability, 2018). To address this concern for this study, Qualtrics, the survey platform used for this study, provided custom validation for potential respondents who click on “autistic adult with a guardian” to then exclude that respondent from the survey. (Custom validation also excluded non-U.S. citizens.) Otherwise, this research design intentionally moves away from the historically paternalistic or protectionist approach. The participation in the survey was voluntary, and the researcher provided no inducements to participate.

The survey asked positive questions, not only to determine what communities are doing to support autistic adults but also to minimize discomfort to respondents and reduce risk of harm. It would be more traumatic for autistic adults to discover post-publication that a community study had been performed about them without their input. Additionally, the potential findings of this study outweigh potential risks by providing the groundwork for self-advocates, advocates,
families, community developers, and policymakers upon which to build sustainable and inclusive communities for our most marginalized.

**Confidentiality**

In Ipsen, Seekins, Arnold and Kraync’s 2006 study one of the four participants did not like being identified as a person with disabilities, which can be an issue for autistic persons because of media-driven stereotypes mentioned earlier or fear of further marginalization. Confidentiality was primacy in this study, not only for IRB compliance but also to ensure respondent participation and to reduce stress for autistic adults who may be concerned that their communities might discover that they have autism. No identifiers, such as ZIP codes, email addresses, usernames, internet protocol addresses or names were collected. Regionally identifiable brand names, for example, grocery store or restaurant names, were deleted before analysis. The only geographically comparable data requested was whether the individual lives in a metropolitan, micropolitan or rural area. The distribution of the survey through snowball sampling protected the anonymity of the respondent from the researcher. The only personal identifier that would then remain was a signed consent form. Therefore, the researcher requested a consent process versus a signed consent.

**Consent process**

According to Kuchera and Logsdon (2017), the Office for Human Research Protections “considers subject recruitment to be the beginning of the informed consent process.” They note that IRB approval is not required if the advertisement contains only title, purpose, study summary, basic eligibility criteria, study site location, and contact information (Appendix B). The initial step in recruitment occurred by sending the advertisement to the 15 social media
websites and organizations with a combined following of 3.6 million followers for dissemination.

The electronic consent (Appendix C) was written on a 4.5 grade reading level as measured by the Flesch-Kincaid Grade Level test without the title and investigator information. The title, investigator and IRB information raise the reading grade level to 6.9. (The investigator and IRB information was written at an 18.8 grade level and was unavoidable.) The readability level of the electronic consent process was sufficiently low enough for the common reader, but high enough to filter those unable to read at that level.

The consent process included a “live button” at the end of the consent form that stated, “Clicking below indicates that I have read the description of the study and I agree to participate in the study.” By clicking on the “live button,” the respondent actively demonstrated their willing consent to participate.

Archival Records

Archival records, such as public records, mass media, and private holdings can provide an abundance of data for researchers, especially since the introduction of the internet. Internet sites such as TED (Technology, Entertainment, and Design) and its’ affiliates, along with YouTube, provide visual media platforms for people around the world to share their own stories, offering researchers primary qualitative data for collection and analysis. Those sites will be used in place of interviews and focus groups. TED and YouTube videos will be chosen using a process extracted from Frankfort-Nachmias et al.’s “What is Said” Categories (2015) for content analysis as discussed in the subsequent section for replicability. Also available for this study were 14 years of journal and social media entries by this activist-participant researcher, first-hand accounting of experiences from a parental point of view.
Analytical Framework

The Discovery and Dream phases of Appreciative Inquiry (AI) included collecting and organizing the data for a mixed-methods content analysis. Content analysis of what was said in the surveys, videos, and journal/social media entries reduced the data to Thematic codes that consisted of the seven capitals (human, cultural, social, financial, built, political, and natural) from the Community Capitals Framework, and sub-coding actions that answer the research question within those seven capitals. The qualitative method of in vivo coding provided the personal voices of autistics and their family members in the body of the text that the other analyses did not.

Content Analysis

Content analysis allows a researcher to reduce larger amounts of data, including interviews and artifacts, to key ideas or themes based on a set of criteria (Frankfort-Nachmias, Nachmias and DeWaard, 2015; GAO, 1996). Content analysis can examine the message itself, what the message says about the writer or speaker, and the impact on those hearing or reading the message. This study focused on the message itself and what was said by self-advocates, family members, and friends. Data selection criteria is typically used to eliminate data bias supporting the researcher’s hypothesis. However, this study is biased toward what is working favorably – eschewing the medical and charity models -- for autistic adults from the autism community’s point of view in a critical studies approach. The researcher adopted Frankfort-Nachmias et al.’s applicable “What is Said” Categories (2015, p. 277), shown in the process in Figure 6, during the content analysis.
Community Capitals Framework

The Community Capitals Framework provides a means for researchers to break down the whole of a complex system into its sub-systems from an asset-based, empowering approached (Roseland, 2012; Gutierrez-Montes, Emery, and Fernandez-Baca, 2009). The assets within those sub-systems -- or community capitals -- are mapped visually, as in Figure 7 to provide a concrete reference of those assets and how they may interplay with one another; therefore, if an investment is made in one asset, community developers would expect to see benefits in other capitals as well, (Flora and Flora, 2013: Roseland, 2012; Gutierrez-Montes, Emery, and Fernandez-Baca, 2009; Emery, Fey, and Flora, 2006). Content analysis provides researchers a way to condense large data into smaller units, such as themes or items. In this study, survey responses, videos, and personal journal entries were coded using the seven capitals of the Community Capitals Framework (built, financial, social, cultural, human, political, and natural

Figure 6. Process used in content analysis of surveys, TED and YouTube videos. Note. From Frankfort-Nachmias, Nachmias, and DeWaard, 2015, p. 277.

- **Authority**
  - **Who makes the statements?**
  - Only autistic adults, family members and friends were considered.

- **Traits/Direction**
  - What characteristics are used in describing the people, and how is the subject matter treated?
  - Artifacts using deficit-based models were excluded.

- **Subject Matter**
  - What is the communication about?
  - Thematic coding using one of the seven community capitals: built, financial, social, human, natural, cultural, and political.

- **Methods**
  - What methods are/could be used to achieve inclusion and independence?
  - Sub-coded under Thematic codes.

- **Values**
  - What values, goals, or desires are revealed?
  - In vivo coding is used to preserve participant’s experience.
capitals) as thematic codes. Therefore, when respondents or video participants talked about employment, employment (the sub-code) was listed under the Thematic code “Financial Capital.” If a respondent provided a compelling statement, then that statement was included in the body of this study using in vivo coding.

Figure 7. Community capitals’ asset map illustrating the community capitals and their overlap. Note. From Emery, Fey, and Flora, 2006.
CHAPTER 4. FINDINGS

The total number of responses to the AI survey following five months of publication were statistically insignificant, and no statistically reliable conclusions can be drawn from the survey data. There were concerns throughout the study development phase of low response rate and a lack of inducement to participate (Frankfort-Nachmias, Nachmias and DeWaard, 2015). However, the researcher believed that those obstacles could be overcome with publication to potentially 3.6 million social media followers of those 15 organizations and guaranteeing autistic adults a seat at the table. The response rate to Gillespie-Lynch et al.’s online study (2017), which netted 636 respondents without inducements, confirms that a large response rate is possible.

Despite the low response rate, of the eight answers provided, seven highlighted investments in human capital. One of the eight answers was classified as cultural capital. Explanation of the classifications are included in the respective sections.

Failure to Deliver

Of the 15 organizations, only two [(O1 and O2)]– one with a large following, the other with a small following – published the study one time each on their respective sites with nearly two million followers. Although both organizations work on autism or disability issues, neither may have a significant following of the targeted demographics for different reasons. One is a University Center for Excellence in Developmental Disabilities, Education and Research, and therefore may only be followed by academicians. The other has alienated many in the community by focusing on a “cure” for a genetic anomaly versus concrete and measurable supports for the community for which it is perceived to represent. Table 5 provides a synopsis of the organizations. One unknown variable is the social media algorithms, who saw the advertisement and how many times it may have crossed someone’s feed.
Table 5. Documentation of contacts and publication responses from 15 organizations.

<table>
<thead>
<tr>
<th>Org.</th>
<th>Times Contacted</th>
<th>Published</th>
<th>Contact Confirmed</th>
<th>If not published, reason provided.</th>
<th>Additional comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>O1</td>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>O2</td>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>O3</td>
<td>1</td>
<td>No</td>
<td>Yes</td>
<td>No inducements</td>
<td></td>
</tr>
<tr>
<td>O4</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td>Unable to determine.</td>
<td>Doctorate study ad published directly on social media after IRB approval for this study.</td>
</tr>
<tr>
<td>O5</td>
<td>2</td>
<td>No</td>
<td>Yes</td>
<td>No response on first contact or follow-up.</td>
<td></td>
</tr>
<tr>
<td>O6</td>
<td>1</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td>Page moderated by O1, but not published on second site.</td>
</tr>
<tr>
<td>O7</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>Closed group website. No alternative contact.</td>
<td></td>
</tr>
<tr>
<td>O8</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td>Auto-response on email.</td>
<td></td>
</tr>
<tr>
<td>O9</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td></td>
<td>The same point of contact as O8.</td>
</tr>
<tr>
<td>O10</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Social media went inactive and website shut down.</td>
</tr>
<tr>
<td>O11</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td></td>
<td>Two auto-response apologizing for backlog on publication.</td>
</tr>
<tr>
<td>O12</td>
<td>3</td>
<td>Not at this time.</td>
<td>Direct contact via phone after initial email.</td>
<td></td>
<td>Turnover at organization.</td>
</tr>
<tr>
<td>O13</td>
<td>3</td>
<td>Not to organization's account.</td>
<td>Direct contact via phone after initial email.</td>
<td></td>
<td>General email lost. Second was sent to specific person. May publish if it addresses their mission. (Published to individual's social media.)</td>
</tr>
<tr>
<td>O14</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>No answer at available phone number.</td>
</tr>
<tr>
<td>O15</td>
<td>3</td>
<td>Not at this time.</td>
<td>Direct contact via phone after initial email.</td>
<td></td>
<td>General email lost. Second sent to specific person.</td>
</tr>
</tbody>
</table>
Lessons learned

The email contained the introductory text while the advertisement was in an attachment, which organizations and companies are cautioned against opening unless they know the sender. In follow-up phone conversations with O12-O15 staff, those organizations do not focus on any one disability, or they focus on specific issues, such as employment or physical design, and, therefore, did not see that the survey aligned with their mission statements.

Those site administrators who are not backed by paid organizations, usually self-advocates or family members, may not have time to filter through all of the correspondence that they may receive, which poses other questions. Did those organizations without phone contacts even receive their emails? Did the emails go to spam or did the subject line (adult autism study) even invite those who did receive the email to open it?

Iowa State University is not a member of the Association of University Centers on Disabilities or a University Centers for Excellence in Developmental Disabilities Education, Research, and Service (AUCD/UCEDD), nor are any of the universities in the Great Plains Interactive Distance Education Alliance community development program. AUCDs/UCEDDs work to promote inclusion, independence, and self-determination for people with disabilities, including those with developmental disabilities. The unfamiliarity of the university system with the disability rights movement, along with the need to garner IRB approval expeditiously due to time constraints, the researcher thought it necessary to include extra safeguards by not explicitly asking participants to share the survey link, as well as using organizations as a conduit for publication.

Using the organizations as a permissory conduit to publication worked as a gatekeeper, however, whether that was the organization’s intent or not. Compare this survey’s negligible
response to that of the 636 participants, 309 of whom were autistic, in the Gillespie-Lynch et al. 2017 study\textsuperscript{12} which posted directly to various social media sites. (The Gillespie-Lynch study also provided an opportunity for respondents to elaborate on survey questions. The number of responses were sufficiently large enough that it was impractical for the team to code all of the responses.) Although this researcher focused on a single familiar social media, Gillespie-Lynch et al. published their advertisement directly onto a variety of sites including Facebook, Meetup, Reddit, Tumblr, Twitter, as well as general online classified pages. Additionally, one of the researchers in the Gillespie-Lynch et al. study has autism, providing that study social capital that this researcher, ultimately, does not have as a parent. If approval can be gained through a committee and IRB, it is better “to ask forgiveness than permission” from the social media administrators. (The Gillespie-Lynch study does not state how long the study was open.)

**Respondent Demographics**

Eleven responses were recorded using the Qualtrics software. It appears from the responses that the survey worked as it was intended, primarily by excluding individuals with a guardian. Two exited before the consent process was completed. They could have exited the study voluntarily, or it is possible that they were excluded at that point because they were either under 21 years of age or not a U.S. citizen. Three adults with guardians were excluded from the study. Of the six remaining respondents completing the consent process and demographic questions in Table 6, all of the autistic adults represented had official diagnoses of autism and lived in private homes. The six respondents represented individuals who were equally distributed across metropolitan, micropolitan, and rural areas. Only three of those completing the

\textsuperscript{12} The Gillespie-Lynch et al. study included a demographics questionnaire, a pre-test, a training module, a post-test, open-ended questions, and an autism screener.
demographic portion of the survey also answered questions in the open-ended survey section.

The mean response time of those completing the open-ended survey section was 4:31.

Table 6. The demographics of respondents to the Appreciative Inquiry survey.

<table>
<thead>
<tr>
<th>Respondent #</th>
<th>Respondent is…</th>
<th>Autistic adult lives in metropolitan, micropolitan or rural area?</th>
<th>Does the autistic adult live in a group home, private home or other?</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>Autistic adult</td>
<td>Micropolitan</td>
<td>Private home</td>
</tr>
<tr>
<td>R2</td>
<td>Autistic adult</td>
<td>Micropolitan</td>
<td>Private home</td>
</tr>
<tr>
<td>R3</td>
<td>Family member</td>
<td>Rural</td>
<td>Private home</td>
</tr>
<tr>
<td>R4</td>
<td>Family member</td>
<td>Rural</td>
<td>Private home</td>
</tr>
<tr>
<td>R5</td>
<td>Autistic adult</td>
<td>Metropolitan</td>
<td>Private home</td>
</tr>
<tr>
<td>R6</td>
<td>Autistic adult</td>
<td>Metropolitan</td>
<td>Private home</td>
</tr>
</tbody>
</table>

Qualitative data: Community capitals framework

The purpose of this study was to discover what communities are doing from a community development perspective to accommodate and support autistic adults. The Community Capitals Framework was chosen to chart the findings visually and to show the interrelations between the community capitals. The community capitals – or thematic codes – discovered in this study (human capital, cultural capital, social capital, financial capital, and built capital) are discussed in depth in the following subsections. Subcodes, steps that communities and families are doing within those capitals, are bold and italicized in the text. The community capitals map for this study is in Appendix D.

Human capital

Flora and Flora define as “…the assets each person possesses: health, formal education, skills, knowledge, leadership, and talents…. (Human capital) is far more than educational attainment” (2013, p. 84). Seven of the eight survey responses fell within the human capital
domain; however, six of those seven responses, provided in Table 7, reflected the assets or deficits of others’ human capital.

Table 7. Open-ended survey responses that reflected Human Capital.

<table>
<thead>
<tr>
<th>Respondent #</th>
<th>Q1: Tell me about an event or place where you have felt valued and welcomed. Describe more about your experiences.</th>
<th>Q2: Tell me what your community can do to help you feel valued and welcomed more consistently.</th>
<th>Q3: Tell me about a time when you were empowered to advocate for change. Tell me what the issue was. Your proposed change. Tell me how the issue was resolved.</th>
</tr>
</thead>
<tbody>
<tr>
<td>R4</td>
<td>Family member with autism went through meltdown in a diner. The owner told us everything is ok and to not worry about anything else.</td>
<td>Not give condescending looks.</td>
<td>A store would not allow a registered service dog inside the location. Once informed what ADA was, they had no choice but to allow us inside.</td>
</tr>
<tr>
<td>R5</td>
<td>--</td>
<td>Having more small businesses that accepted people with autism by employing them.</td>
<td>(No response given.)</td>
</tr>
<tr>
<td>R6</td>
<td>I felt valued and welcome when I go to conferences or work with people that allow me to speak about disability justice.</td>
<td>Give me accommodations and train my teachers in the post secondary school as well social programs for the disabled.</td>
<td>I was empowered when I was discriminated against which gave me strength and the will to fight back and speak up.</td>
</tr>
</tbody>
</table>

Respondent 6’s answer to questions #2 was broken down into three separate responses where the respondent used the conjunctions “and” and “as well,” as shown in Table 8. Of the
nine responses that were sub-coded as Human Capital assets, six were sub-coded as *tolerance*, two as *leadership*, one as *education* (of others), and one as *social programs*. The initial sub-code for “tolerance” was “compassion”; however, it is synonymous with pity, which is not what is sought. “Acceptance” seemed insufficient. Finally, “tolerance” was decided upon, defined by Merriam-Webster Dictionary as “willingness to accept feelings, habits, or beliefs that are different from your own” or, as dictionary.com states “freedom from bigotry.”

*Table 8. The Sub-coding of responses related to Human Capital.*

<table>
<thead>
<tr>
<th>Responses</th>
<th>Sub-code</th>
</tr>
</thead>
<tbody>
<tr>
<td>The owner told us everything is ok and to not worry about anything else.</td>
<td>tolerance</td>
</tr>
<tr>
<td>Not give condescending looks.</td>
<td>tolerance</td>
</tr>
<tr>
<td>Once informed what ADA was, they had no choice but to allow us inside.</td>
<td>leadership</td>
</tr>
<tr>
<td>Having more small businesses that accepted people with autism by employing them.</td>
<td>tolerance</td>
</tr>
<tr>
<td>I felt valued and welcome when I go to conferences or work with people that allow me to speak about disability justice</td>
<td>tolerance</td>
</tr>
<tr>
<td>Give me accommodations and train my teachers in the post secondary school as well social programs for the disabled</td>
<td>Give me accommodations</td>
</tr>
<tr>
<td></td>
<td>Train my teachers</td>
</tr>
<tr>
<td></td>
<td>Social programs for the disabled</td>
</tr>
<tr>
<td>I was empowered when I was discriminated against which gave me strength and the will to fight back and speak up</td>
<td>leadership</td>
</tr>
</tbody>
</table>

The “condescending looks” mentioned by R4 are familiar to many in the autism community and are mentioned by parents in the Autism 200 series archived on YouTube by the Seattle Children's/University of Washington Adult Autism Clinic. The “look” follows an individual’s meltdown (which are not tantrums) that occurs in public, as father Randy pointed out (SeattleChildrens, 2015) because his child did not have language skills to communicate, shrieking was her mode of communication. The same was the case for this researcher’s child, who was typically triggered into a meltdown by having to leave a place earlier than expected or a change in routine, and, at the time had severe deficits in both expressive and receptive languages. One such episode occurred when we were visiting a store whose environment is equivalent to a library. We suddenly needed to leave because he had had an accident, but he was having none of
it. (We would normally spend hours in the store looking for every Paramount VCR tape/DVD that they had.) The meltdown proceeded in full force and was sufficiently long enough that a manager came to check on the commotion. Fortunately, when he saw who it was – and having seen us often enough to know that the distressed child was my son – he turned and went back to his work. I was finally able to get the three children in the car and return to the store to pay for items for the older two because they should not have been penalized. As I was standing in line, waiting to pay, the woman behind me leaned into me and said softly, “I am a special ed teacher. You are doing a great job, Mom.” The tears that I had been holding back began to flow freely. That same tolerance shown by the employee and the special education teacher is the same acceptance sought time and again in videos of autistic adults who explain what life is like as an autistic. The antithesis to that shopping scene occurred when Son was about three years old, small enough to still sit in a shopping cart seat. The scene was similar: rushing to get through shopping. This time we were at a checkout on aisle one next to customer service with a wide lane between checkout and the customer service counter. Son was in a meltdown because he had been rushed through his favorite department again. As I was trying to calm him, a meddlesome 70-something-year-old woman approached and began attempting to shame Son into silence. Looking her directly in her eyes, I asked her twice to “please, leave,” knowing that Son could quickly turn his rage on her. Instead, while I was distracted by the woman, Son suddenly slapped me hard enough to leave a mark on my face. She was shocked, but even more so that I did not proceed with the Southern disciplinary action of “whoopin’ his butt.” It would have helped immensely if one of the employees at customer service, watching the scene unfold, had interjected, “Mrs. So-and-So, how is So-and-So doing?” to extract her from the situation. Several communities across America have coined themselves “autism-friendly,” including educating
businesses and employees about autism. No details are provided, however, about what that the training entails. (Son eventually gained enough receptive language skills that, if we need to make a quick exit, he understands what I am communicating.)

R5’s response (“Having more small businesses that accept people with autism by employing them”) to the question, “Tell me what your community can do to help you feel valued and welcomed more consistently” could have easily been classified as financial capital at first blush. However, the asset that the respondent mentions here is in the human capital – tolerance from others – so that people with autism are ultimately employed. Respondent #6’s request regarding accommodations, specifically from professors, requires tolerance, as well. For those on the autism spectrum sudden changes, as mentioned earlier, can be significantly challenging. A change in the syllabus or course material requires sufficient notice, just as a store changing hours of service or even the layout of the store, to accommodate those with autism. The accommodations are contingent upon the individual’s needs, which also requires self-advocacy, or leadership, skills.

It takes self-advocates/advocates at times to demand accommodations and modifications to participate in daily activities, which speaks to R4 and R6’s responses – service dog education and empowered when discriminated against, respectively -- to question 3: leadership skills. In her book, How Change Happens (2018), Leslie R. Crutchfield analyzes successful movements that are “leaderfull” to create sustained social change versus “leaderless” or “leaderled” movements. According to Crutchfield, it takes leaders at all levels – local, regional, state, national, even international – to bring about sustained change, and R4 and R6 have stepped into a leadership role on some level. We are seeing the results in the autism movement as people become more vocal demanding April be known as “Autism Acceptance Month” versus the past
“Autism Awareness Month” As part of the push back, self-advocates and allies have adopted #RedInstead and #LightItUpGold in social media and dismiss the famed puzzle piece in favor of an infinity symbol.

Even though none of the respondents mentioned guardianship, regrettably, this study was designed to exclude individuals with guardians in compliance with the Institutional Review Board (IRB Approval, Appendix E) and the adopted guidelines for vulnerable populations, as discussed earlier. Guardianship, however, violates basic citizenship rights by potentially nullifying an individual’s right to vote, marriage, drive, and work (National Council on Disability, 2018), and, for that reason, is not listed as an asset in the Community Capitals Framework. In full disclosure, this researcher is the guardian of an adult son, but that does not mean he does not get to rent his favorite movies a dozen times a month on pay-per-view. He knows how to rent them, even though he has both movies on DVD. It is his money, after all. However, it does give the guardian legal standing if he decides to elope, which he has done, and is an issue for some with autism that has had deadly consequences.

Guardianship/conservatorship can be – and has been – a tool of abuse, especially when money or property is involved, and sexual autonomy (National Council on Disability, 2018; Government Accounting Office, 2010). Additionally, guardians can override an individual’s choice to community living, and, instead, unnecessarily place the individual in an institutional setting or even a less restrictive community setting where they wish not to be. For us, there are no sufficient alternatives between independence, especially protecting his right to vote13, and

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13 Only California, Maryland, Nevada, and New Mexico have adopted the American Bar Association’s House of Delegate standard that an individual’s right to vote should only be removed if the individual “cannot express ‘a specific desire to participate in the voting process’” (National Council on Disability, 2018, p. 106).
guardianship (protecting his life). (Marriage for him would be accommodated through co-habitation, if necessary.) Powers of attorney are a less restrictive and far less costly option than guardianship but can still be subject to the same abuse as guardianship. Advanced health directives, depending on state laws, may be used for healthcare needs. (Financial tools are discussed in the financial capital section.)

There are movements in the disability community against guardianship toward less-infringing alternatives, such as supported decision making (SDM) to protect an individual’s self-determination. SDMs use a supporter or group of supporters to advise or translate to others the individual’s decisions. SDMs can be used in conjunction with guardianships, as this researcher does with her son. The importance of SDMs – even in conjunction with guardianships to the greatest extent possible – is that the individual’s wishes are honored. The neurodiverse, like neurotypicals, are lifelong learners, which may speak to R6’s response of “social programs.” Mothers, like Joy (SeattleChildrens, 2015), stress over experts’ emphasis about the timeframe for language acquisition never questioning that many neurotypicals learn second languages as adults. Autistics learn to date (CBC News, 2016; Decomas, 2012). Many learn self-care because dating or a job is important to them (Decomas, 2012). And Kirsten, who was made fun of in elementary school because of her hand-flapping stopped the self-stimulatory behavior when she observed herself doing it in front of a mirror “and decided to stop doing it in public” (Decomas, 2012). Kirsten also used audio recordings to learn voice inflections, a challenge for many on the autism spectrum. The National Council on Disability, though, notes the gaps in research, in particular of unintended consequences with supported decision making. One of the arguments against guardianship is an individual’s “right to experience the dignity of risk” (p. 27) – the right to make errors while learning; however, one of the unintended consequences it fails to discuss is the
role of the judicial system and subsequent incarceration in that right to learn, and fatalities associated with “dignity of risk.” The United Nations Committee on the Rights of Persons with Disabilities (CRPD), however, takes a hardline stance against guardianship in Article 12, which addresses “equal recognition before the law” (National Council on Disability, 2018; Dept. of Economic and Social Affairs, n.d.). The United States is only one of 12 countries that has not ratified the CRPD, and the only developed country that has not signed.

**Cultural Capital**

Cultural capital is who we are as a people, “…who we know and feel comfortable with, what heritages are valued…and generations…” (Emery, Fey, and Flora, 2006, p. 5). For communities of place, cultural capital may include local festivals and events, but for families and individuals with autism, it is shared lived experiences that create the cultural capital. When queried, “Tell me what your community can do to help you feel valued and welcomed more consistently,” R5 responded, “I live with my parents.” This response could have easily been classified under social capital, human capital, or even built capital (housing); however, for R5, it appears that they have a significant support system with their parents.

Nancy, Nina’s mother, and Pam, Ben’s mom, (SeattleChildrens, 2015) are two parents who explain what inclusion is like in the special needs community, in general, and the autism community, in particular. “(A community of special needs parent friends) understand your life like nobody else. And even our closest friends and our family – as well-meaning as they might have been – they just can’t get it in the same way that other special needs parents can,” Nancy said. Pam reiterated the point, stating, “Eventually, you’re going to embrace autism as part of your identity…. Autism is a part of who we are as a society. Like everything. I am a parent of a child with autism. I am an autism parent. That’s part of my identity. And you get to a point
where you don’t think ‘Gosh, I wish I wasn’t a parent with autism,’ any more than I think, ‘Gosh, I wish I wasn’t a woman. You know, life would be so much easier if I were a man. I’m so mad I’m a woman.’ You don’t think like that. It is a part of who you are, and it becomes a really great part of who you are and who your child is,” Pam, Ben’s mother.

Unfortunately, some parents may never get to the realization that Pam related, instead remaining, as some equate, in the stages of denial, anger, and depression of the grieving process. Quoting a 1966 article in *Time* magazine in which the author called homosexuality a “pernicious sickness,” TEDMED speaker Andrew Solomon in 2013 asked, “How did we get from there to here? How did an illness become an identity?” After writing an article on Deaf culture for *The New York Times Magazine* – a demographics he initially viewed pitifully and as an illness – and following a friend’s birth of a child with dwarfism, Solomon realized the similarity between some straight parents (including his mother) who want their children to “function in a mainstream world” and parents of children with a “disability” who tries to “cure” their child. From this, Solomon concluded that there are two kinds of identities. *Vertical identities* are those characteristics passed down from generation to generation (ethnicity, nationality, language, religion, etc.) for which, typically, no “cure” is sought. *Horizontal identities*, as Solomon contends, are those identities that are foreign to parents and which they try to “cure,” but are learned from a peer group. Solomon also quoted from a 1968 copy of *The Atlantic Monthly* in which a noted bioethicist deemed that individuals with Down Syndrome “is not a person.” Ultimately, Solomon quotes Jim Sinclair, an autism activist: “When parents say, ‘I wish my child did not have autism’ what they’re really saying is ‘I wish the child I have did not exist, and I had a different, non-autistic child instead.’ Read that again. This is what we hear when you mourn
over our existence. This is what we hear when you pray for a cure – that your fondest wish for us is that someday we will cease to be and strangers you can love will move in behind our faces.”

Autism culture is about *schedules* and *routines*, perhaps Barney and The Wiggles for a lifetime, particular foods and restaurants, and – for many – long-term planning, including housing, and daily adult life, as well as possible caps on insurance, which Ellen, older sibling to John and Carrie who are at differing points on the autism spectrum, discussed (SeattleChildrens, 2015). *Siblings* can play a huge role in autism culture as observers and participants. Ellen was incorporated into her parents’ will as her siblings’ guardian when she was 13 years old. She was Ph.D. student in clinical psychology researching autism at the time of the Seattle Children’s interview. She explained what long-term planning is like for her, reflecting the experiences of many siblings: “I think I always have a secret plan in the back of my mind. Like, okay, I live in Seattle now. My family is far away, but if something were to happen, I kind of have a plan in place. ‘Okay, this is what we’re going to do.’”

**Social Capital**

Social capital is the relational and network interactions that are part of everyday society (Flora and Flora, 2013; Putnam, 2000). Putnam and Flora and Flora distinguish between bonding social capital (those who have similar interests and backgrounds) and bridging social capital (the connection of diverse groups). The authors emphasize the importance of both bridging and bonding social capital in community development. Flora and Flora (2013) drive home the importance of social capital on health – in the absence of financial capital – referring to the impact Hurricane Katrina had on the poor in New Orleans in 2005, adding, “People in communities that lack social capital are more likely to experience stress, hypertension, and mental health problems, among other difficulties” (p. 129). From this researcher’s long-time
observations, in the absence of bridging social capital, parents are more susceptible to dangerous “cures,” pharmacological-based treatments for their children, charity models, and, generally, poorer outcomes for their children than those parents who have access to bridging capital. Also, as discussed in Chapter 1 of this study, social exclusion increases the likelihood of poverty (Flora and Flora, 2013; Pigg, Gasteyer, Martin, Apaliyah and Keating, 2015; DFID, 2005; Putnam, 2000).

By the very nature of autism, autistics are challenged to develop and maintain social capital. The absence of social capital for autistics can even magnify autistic traits, and, for the individuals, social capital development may need to be intentional in design as the social enterprise venture – Rising Tide Carwash – is for Andrew D’Eri (TEDx Talks, 2014), or clubs or meetups for Ben (SeattleChildrens, 2014). (Social enterprise is included here if it is considered a hobby by Internal Revenue Service guidelines.) “If you’re not going to college, if you don’t have a job, if you’re not volunteering, if you’re sitting around at home all day at some point, you’re probably going to get pretty lonely, and, I think the best thing to do is find something that you like to do that is a group activity. You know, the best way to meet people is to get out there,” Ben said. Others mentioned were internships and volunteering. These are included in social capital in this study because interning or volunteering may or may not lead to financial capital. For this researcher-mother, the intentional design of social capital for Son who is nonverbal is to build a circle of support for him so that there are several people who have visual contact with him on a daily basis to ensure his well-being and to, at least, maintain the immense gains he has made in language and social skills. Social capital also offsets the potential isolation that can come with guardianship issues. As one interviewee stated in the guardianship report published by the National Council on Disability, “The good guardian is going to ensure
that there is integration into the community[,]…that they receive the socialization, the community interaction, the community respect that they are do [sic] and that’s what a good guardian does” (2018, p. 159).

**Financial Capital**

Like Respondent 5, many panelists on the YouTube videos mentioned having or wanting jobs (SeattleChildrens, 2016; SeattleChildrens, 2014; Decomas, 2012). As Shaffer, Deller and Marcouiller (2004, p. 102) stated, “…(J)obs are central to society and personal perception of worth, preparing people for work, placing and keeping them in jobs, and providing opportunities for advancement are critical.” The first corporation this researcher knew where autistic adults were intentionally employed was at Walgreens’ distribution centers in 2007, and has served as a model for Best Buy, Lowe’s, and P&G (Putterman, 2018). Since then, tech giants Microsoft and Apple, as well as lesser-known companies like Specialisterne, have seen the added-value of hiring people with autism. The push for employees on the spectrum in tech industries, though, poses a risk of other businesses stereotyping individuals with autism as the case has been with other minority populations. Putterman provides 16 principles for those seeking to hire persons with special needs, including, “don’t underestimate the abilities of employees with special needs,” and “apply the same performance standards for all employees.” One of the issues to moving the needle on employment issues for persons with disabilities is stated by Bill Novelli, who authored the foreword in Crutchfield’s book, *How Change Happens*. Novelli leads the Global Social Enterprise at Georgetown University and has worked with the Viscardi Center.

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14 The Viscardi Center was founded by Dr. Henry Viscardi Jr., who wore prosthetic legs and served as disability advisor to eight Presidents from Franklin D. Roosevelt to Jimmy Carter. The Center works on lifespan issues for persons with disabilities from education to employment and “pro-active efforts that aim to shape and influence policy changes that will benefit the people it serves” (The Viscardi Center, 2019).
and the U.S. Department of Labor’s Office of Disability Employment Policy on employment issues for persons with disabilities. In the organizations’ research, they found that “small- and medium-sized businesses operating at local and regional levels in different parts of the country shows that many HR directors don’t even think of disability as part of diversity and inclusion. So we need to start there, not down the road” (Crutchfield, 2018, p. xi). Novelli’s findings may reflect the sentiments of social justice organizations mentioned in Chapter 1 of this study who, during their litany of marginalized populations fail to recognize disabilities.

Disability rights activists are making strides in opening industries to our people on the spectrum. Unfortunately, we may face significant challenges in finding fair market employment for our people on the lower end of the autism spectrum, those who face significant communication challenges, or those who live in areas of the country that face intractable unemployment numbers, even for the typical population. Social enterprises (Stolman, 2018; Caldwell, 2014), self-employment, and similar models, such as micro-enterprises (Griffin, Hammis, Keeton and Sullivan, 2014; Balcazar, Kuchak, Dimpfl, Sariepella and Alvarado, 2014; Walls, Dowler, Cordingly, Orslene and Greer, 2001), and cooperatives (Bishop, 2013) may be necessary to ensure a place in the economy. Following the launch of Rising Tide Carwash, Tom D’Eri began Rising Tide U to help guide autistics and their families through starting businesses.

Historically, employment for persons with disabilities has resulted in loss of entitlements, such as Supplemental Security Income (SSI), Social Security Disability Income (SSDI), and Medicaid. However, with the passage of the Achieving a Better Life Experience (ABLE) Act of 2014 allows the individuals, families, and friends to deposit up to $15,000 into a 529A account without losing benefits. States set the maximum limit over time with many capping contributions at $300,000. For those receiving SSI, however, that benefit will be suspended when the account
reaches $100,000 and until the account balance falls below $100,000; however, it does not affect their Medicaid. Monies from a 529A can only go toward certain expenditures, such as housing, transportation, education, health care expenses, etc. There is cause for concern, though, as the current cost for states to manage 529A accounts are currently exceeding those enrolled (Diament, 2018). For those who will need lifelong supports, estate planning – which may include special needs trusts, pooled trusts, life insurance for family members -- is critical. Families should consult an estate or special needs trust attorney for guidance.

Built capital

Ohio State University’s regional planning students released their *Autism and Planning Design Guidelines 1.0* in 2018 (Knowlton School of Architecture) based on their “Six Feelings Framework:” feel connected, feel free, feel clear, feel private, feel safe, and feel calm. The findings were based on two focus groups, one with autistic adults, and the other with parents of autistic adults. The work is based in urban design and invites dialogue moving forward. The Knowlton study will not be restated here, except with regards to crosswalks and sidewalks. The study recommends magenta paint for crosswalks, which should be 10’ wide. From our own experiences, I would concur with this because Son does not acknowledge white crosswalk signage, and current crosswalk widths typically do not allow room for caregivers to walk side-by-side with their charges amidst other pedestrians. The study also recommended sidewalks 13’ wide, with an 8’ walking surface to allow three people to walk side-by-side instead of two, thus reducing sensory overload by minimizing congestion. The difference between the sidewalk width and the walking surface includes a three-feet tall, one-foot-wide barrier between foot and road traffic, as well as a four-foot-wide planting strip between the barrier and the street. These are

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15 See the Knowlton study for accommodations for focus groups involving autistic adults.
ideal recommendations for those caregivers who care for “runners” – those on the autism spectrum who suddenly bolt.

The Knowlton study’s target demographics for change are city and regional planners, engineers, real estate developers, and related industries. The housing section of this study certainly applies to those industries; however, the section in this study takes on a discussion of how the Fair Housing Act can fall short for families and individuals with autism and includes personal discussions of housing options for Son.

Housing

None of the survey respondents mentioned housing, specifically, which is a long-term worry for many parents and siblings like Ellen. Parents of any child, including neurotypical adult children, will always worry. It comes with the job. But for those parents with children on the autism spectrum, that worry is magnified hundreds of times over. A recent study by Churchard, Ryder, Greenhill, and Mandy (2018) found that in one British inner-city area, a significantly greater portion of the homeless population exhibited autistic traits (12.3%) compared to the general population (1%). It is a real concern. Family and autistic adults in panel discussions on YouTube considered for this study mentioned living situations with family – as the survey respondent did -- and having roommates or housemates, which also contribute to social capital.

Several parents also mentioned that their adult children live in group homes. Over the past decade, parents have collectively joined together to create farmsteads, gated communities, and clustered housing for their adult children with autism and intellectual and developmental disabilities that has resulted in a back-and-forth between ideologies and presidential administrations about what constitutes segregated housing. Organizations such as Autistic Self Advocacy Network (Barrows, 2012) took a hardline stance against any congregated housing,
producing a research brief that looked at, not only its own small survey of community versus institutional housing, but also available research in the United States and nationally of the benefits of one versus the drawbacks of the other. The National Council on Disability had also taken a strong stance in 2011 and defined “institutional settings as housing situations in which more than four people with I/DD’ live in a single home” (Lutz, 2015). In 2014 under the Obama administration, Centers for Medicare and Medicaid Services (CMS), which funds states’ Home and Community Based Services (HCBS) Waiver, issued a final ruling against what it deemed segregated housing and jeopardized state HCBS funding for farmsteads, gated communities, and clustered communities, preemptively deeming these housing settings as segregated. Parents and other organizations fought back against the 2014 ruling, arguing discrimination in favor of choice, pointing to clustered housing for college students, retirees, and religious sects (Lutz, 2019). Complicating matters at the time of Lutz’s 2015 article, 80,000 autistic adults were waiting for institutional placement, a wait list that can be ten years long.

CMS, under the Trump administration, recently published clarification on these settings to stress integrated outcomes versus housing location (CMS, 2019). As autistic self-advocates have pointed out, abuse can happen in any setting, including private homes. Because states write the guidelines for their Medicaid – and, ultimately, HCBS -- funding, housing for people with disabilities can look vastly different from state to state. For example, referencing a 2013 Larson et al. study, Autistic Self Advocacy Network (Albrecht and Brown, 2014) pointed out that 84 percent of people with intellectual and developmental disabilities in Nevada live in homes that are owned or leased by individuals with intellectual and developmental disabilities, while only 1 percent of those living in New Jersey do. Options such as shared living (the individual with disabilities owns the home while a tenant pays reduced rent or no rent in exchange for defined
services) or adult foster care (the individual with disabilities moves into a host home) are other models (Kameka, 2016). For autistic adults for whom change is especially challenging adult foster care may be less of an option. Also, as Feinstein et al. (2006) found, home ownership for adults with disabilities resulted in more self-determination and “connectedness” to the community. For autistics, homeownership would provide stability and continuity. This discussion intends to present all sides of a complicated discussion, and alternatives for community planners. However, Flora and Flora’s (2013) argument about the relationship between built capital and social capital is as relevant to the disability community as it is to the others they discussed. They stated, “Rural development policies are often geared toward enhancing built capital on the assumption that people’s lives will improve, particularly people who are disadvantaged, once new physical structures are in place. Yet concentration on built capital while ignoring social capital has led to the installation of rural water systems that have resulted in rural sprawl or gentrification of rural areas to the point that the original residents can no longer afford to live there. Communities are far more than built capital. Built capital can support the life of the community, but it can also exclude certain people (those on ‘the wrong side of the tracks’) and divert financial capital from other investments” (p. 212).

Estate planning for this researcher-mother has hovered over the family for years. Like Ellen, the sibling noted earlier, this researcher’s two typical children have “plans” for their brother in the event I am unable to care for him. Son’s desire is, most likely, to stay in the home I own outright and has been the only home he has ever known. Although he loves his siblings and his sister-in-law dearly, his expressive language severely diminishes when he visits them, so shared living – with community supports – would presumably be his desired choice. However, it may be necessary or desirable for one of his siblings to move him to where they live. Our
discussions, if this were to occur, have evolved around a tiny home (or accessory dwelling unit) or an add-on suite. A duplex may also be an option (Knowlton School of Architecture, 2018).

The Fair Housing Act (ADA.gov, 2009) prohibits housing discrimination based not only on race, color, religion, sex, familial status, and national origin but also disability. The law prohibits discrimination in private and public housing, selling or renting a dwelling, as well as “financing, zoning practices, new construction design.” The majority of the complaints handled by the Fair Housing Enforcement Office, though, deal with discrimination based on disability (O’Byrne and Dale, 2016). Kansas City recently gained recognition for its tiny home village to address veteran homelessness (NowThis News, 2018). As Veterans Community Project Co-found Bryan Meyer said, “Anyone that may have a social anxiety disorder, PTSD, group living situations really are not good for those individuals, and this kind of provides that shelter, that home for them.” Not all towns and cities are welcoming to tiny homes and pass zoning ordinances explicitly prohibiting them or require a minimum square footage for housing within county or city limits (Hanes, 2018). However, zoning ordinances prohibiting tiny homes or excluding group homes (a practice called NIMBY – Not In My Back Yard) may violate the Fair Housing Act since those with disabilities are disproportionately affected by lack of affordable housing (Mayors Innovation Project, n.d.; California Department of Housing and Community Development, n.d.).

**Interior design**

The Knowlton study views design through the singular lens of autism and misses intersectionalities and comorbidities with other impairments (Table 9), in particular, DeafSpace design (DeafSpace, n.d.; Vox, 2016), as well as epilepsy design. Elise Roy’s (2015) TED Talk, “When we design for disability, we all benefit,” discusses how texting was originally developed
for those who are deaf. Now, almost everyone texts. This researcher contends that if we design for autism, there is a greater benefit across the community because of comorbid diagnoses and similar symptoms (intersectionality) with other impairments.

Table 9. Potential comorbid impairments and their rate of incidence with autism.

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Rate of comorbidity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>20-33% of autistics</td>
</tr>
<tr>
<td>Intellectual disabilities</td>
<td>32% (Most common with those who have autism as well as epilepsy.)</td>
</tr>
<tr>
<td>Gastrointestinal disorders</td>
<td>Autistic children are nearly eight times more likely to suffer from one or more GI issue than the general population.</td>
</tr>
<tr>
<td>Disrupted sleep</td>
<td>More than half and possibly as high as 80%</td>
</tr>
<tr>
<td>Feeding/Eating issues</td>
<td>Approximately 70% of children</td>
</tr>
<tr>
<td>Mental Health</td>
<td>ADHD (30-61%); Anxiety disorders (11-42%); Depression (26% of adults); Schizophrenia (4-35% of adults); Bipolar disorder (6-27%).</td>
</tr>
<tr>
<td>Premature Death</td>
<td>Twice as likely to die of premature death. Some subgroups with autism as high as 10 times as likely as the general population (Autism Speaks, 2017a).</td>
</tr>
<tr>
<td>Sensory Processing Disorder</td>
<td>At least 75% of children (STAR Institute, 2018).</td>
</tr>
</tbody>
</table>

Some businesses have begun providing designated *quiet shopping hours* or *calming sensory rooms* to accommodate those on the spectrum. It is illogical though to think that parents and individuals can wait every time until the quiet shopping hours. Larger companies are turning to the triple bottom line of sustainability (Crutchfield, 2018; Roseland, 2012; Cooperrider, Whitney and Stavros, 2008) -- social, economic, and environment – in a time when social and environmental issues matter significantly to customers, and 3.5 million people with autism, their
families, and allies create a significant economic bloc. By adapting to an autism-friendly environment, businesses will make a visible, solid commitment to inclusivity.

- **Muted blues and greens interior** can provide a calming effect for people on the spectrum (Knowlton, 2018) while providing contrast to skin tones for the deaf who sign (DeafSpace, n.d.; Vox, 2016).

- **Diffused lighting** is recommended in DeafSpace design because it reduces eye strain and improves concentration, and incandescent bulbs are suggested for autism design versus fluorescent lighting, which can negatively impact sensory processing disorders, ADHD, and can trigger photosensitive seizures. The Knowlton guidelines specifically recommend **LED or incandescent bulbs in a light yellow color**.

- **Flooring should be shock and acoustically absorbent, such as natural fibers or carpet.** Even linoleum is quieter than tile. Hard flooring, such as tile, can be dangerous for someone experiencing a seizure when they fall (Epilepsy Society, 2016), and reverberations in tiled and cinder block rooms negatively affect not only those on the autism spectrum by providing an assault on the auditory system but also those who are wearing hearing aids, which magnifies everything including background noises. All classrooms with students with autism as well as classrooms with students with hearing impairments have tennis balls on the feet of the chairs and desks.

- **Eliminate the use of perfumes and essential oils.** Finally, although the Knowlton students do not address businesses that are prone to use perfumes and oils as a “memorable” shopping experience, those same oils can be assaulting to not only
those on the autism spectrum but can recall traumatic episodes for those with post-traumatic stress (Vermetten and Bremner, 2003). They can also trigger respiratory issues in those with respiratory illnesses (Canadian Lung Association, 2016).

- **Gender-neutral bathrooms.** Over the past several years, a segment of American society has been empowered by the concept – and laws, where passed – of “transgender bathroom bills.” The transgender population are not the only ones to feel the tension over the bigotry by the emboldened. Those with “invisible disabilities,” such as autism can also be the subject of such discrimination, even when it is evident that the individual is not fully independent. Son has no concept of danger and requires self-care assistance. His caregivers are primarily women, which poses the bathroom dilemma. We inevitably go into the women’s facilities where everyone is afforded privacy. Recently, as I was washing his hands – a clear indication of his impairment -- at a truck stop lavatory, a woman a few sinks over locked eyes with me and maintained eye contact throughout her time at the sink. I thought that we had been liberated once she left the bathroom; however, when we exited the restroom, she immediately made eye contact and did so throughout the store to her exit. Someone later recommended that we use the shower facilities that, they described, are like home restrooms; however, a long wait is impractical, and we are accommodated under the Americans with Disabilities Act in public restrooms.
CHAPTER 5. CONCLUSIONS

This research intended to draw disabilities – as a social design – into the community development field and to expand the idea of what an inclusive and accessible community should look like for autistic adults using the Community Capitals Framework as an informational and analytical tool. The Discovery and Dream phases of Appreciative Inquiry were used to gather the data. The findings show an overall community that is rich in human, built, and financial capitals, and less so in cultural and social capitals. No mention was made of political or natural capitals, which was expected with natural capitals but surprising for political capital. Research in professional community development fields has mostly been silent with regards to a community of place for persons with disabilities.

A 2006 special issue of Community Development: Journal of the Community Development Society focused on community development and disabilities. Half of the articles in that issue were used in this study. The other half were excluded based on the framework of this study. That is not saying they are any less critical. Certainly, Centers for Independent Living (O’Day) would provide expert knowledge and partnership opportunities with the community development field, and Hernandez, Balcazar, Keys, Hidalgo, and Rosen’s article about participatory social action for those with physical accessibility issues provide a model for those seeking to use participatory action with persons with disabilities. Yet, 13 years after then-guest editor Tom Seekins called for “…new opportunities for partnerships between people with disabilities, disability advocates, and community development researchers and practitioners” (p. 1), little has been published regarding what – if anything – has been learned, and graduate community development programs are pondering if – and to whom – community development certificates should be offered. Although community developers may have worked to address
physical accessibility, community developers are unintentionally leaving large segments of the American population behind in poverty by not addressing the social exclusion of those with autism, intellectual and developmental disabilities. What are the possible obstacles for community developers to get from where we are to where we should be, from, as Andrew Solomon said, an illness to an identity?

**Addressing Bias**

As Novelli (Crutchfield, 2018) discussed regarding human resources departments, community development researchers and practitioners may not consider disability a part of diversity and inclusion efforts, and that is where we must begin. Explicit and implicit bias impacts the way neuro-typical people interact with those not only on the higher functioning end of the autism spectrum, those who are socially or conversationally “awkward,” have their own sense of fashion, or speak with a unique voice or vocabulary. People assume that “everyone” with autism is good in math or computers, and they assume that someone who cannot speak does not have the cognitive ability to understand. It is unquestionable whether a “friendship” is based on pity or a power dynamic. An honest assessment of “asset-based community development” research initiatives may reveal that they are more able-centered than based on the true strengths of the person with disabilities. Professional and programmatic self-reflection requires that practitioners and researchers question whether or not the use of community development’s Principle of Good Practice “first, do no harm” preclude them from actively seeking community development input from those with autism, intellectual and developmental disabilities. Or is “community development” for this demographic the sole responsibility of governmental agencies and nonprofits, ignoring the first part of that Community Development Society principle to “incorporate the diverse interests and cultures of the community in the community development
process” (CDS, 2019)? They are the same, yet different, biases that may impact any other minority population. These issues must be addressed to move forward to collaboration and change. The clarion cannot be sounded with enough urgency to stakeholders, as Dr. John McGonigle, Associate Professor of Psychiatry, University of Pittsburgh School of Medicine (Dubinsky, 2015) stressed: “When this group matures – this group that’s been diagnosed in the last ten years – now comes into the community, it’s going to put just an unbelievable strain on an already strained situation…. The autism boom is going to change society.”

**Families, Individuals, and Communities**

Both bridging and bonding social capital can be challenging for individuals with autism and their families. Prejudices from the typical community that favor the medical and charity models, institutionalization and viewing entitlement programs as for only those who work are significant barriers for families and individuals. There are divisions within the autism community as seen in People-first versus identity language and housing issues. The same community building models used in divided communities for neuro-typicals may be beneficial in building bridging and bonding social capitals across and within the autism community. Building those social networks are critical to community sustainability that relies more on community supports and accommodations and less on costlier institutionalization while providing access to essential change information within the autism community.

The lack of cohesive political capital within the autism community is concerning. Organizations such as The Arc and National Down Syndrome Society have lobbied to get such laws as the Achieving a Better Life Experience Act passed. Yet, the leading autism organization, which received more than $50 million in contributions and grants in 2017 only spent $400,000 in lobbying (Autism Speaks, 2017b; Center for Responsive Politics, 2017) at the same time as the hospital and nursing home lobbies spent $100 million, which clearly favors for-profit
institutional care over community settings. As states move to managed care organizations under the guise of controlling cost for those in community settings, the nursing home industry’s role in this is questionable (VanBooven, 2018). Without the social networking supports, an aging parent population, and the lack of transportability of Medicaid Home and Community Based Services across state lines where siblings may reside, individuals with autism may face a greater risk of nursing home care. Also, given the rate of incarceration for people with autism and the mentally ill (Pasha, 2017; Ford, 2015), America appears to be reverting to a different – and far costlier – institutionalization than was previously in place.

Moving Forward

There is no reason to think that community development strategies, based on balanced technical assistance and self-help, that have worked for other minority populations will not work for individuals with autism and their families. Those efforts across community capitals must be directly targeted for inclusion through intentional design and accommodations. Community development organizations are uniquely positioned to view the complex system of disabilities through analysis such as the Community Capital Frameworks and the lens of the “triple bottom line” to address sustainability issues for the autism community. This would begin with a comprehensive survey of literature across fields of study and practice, identifying gaps that lead to further research, writing provocative propositions, and moving forward to create a standard for communities and businesses to become certified as “autism friendly” with autistic individuals’ voices centered first, family second and everyone else’s following.
REFERENCES


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APPENDIX A: APPRECIATIVE INQUIRY SURVEY

I am 21 years or older
  o  Yes
  o  No (custom validation in the Qualtrics software will not let this respondent continue.)

I am:
  •  A U.S. citizen
    o  Yes
    o  No (custom validation in the Qualtrics software will not let this respondent continue)
  •  Autistic adult without a guardian
  •  Autistic adult with a guardian (custom validation in the Qualtrics software will not let this respondent continue)
  •  A family member/caregiver of a person with autism
  •  An unpaid friend of a person with autism

“You” now refers to the person with autism.

You:
  •  Have been diagnosed with autism spectrum disorder by appropriate healthcare officials
  •  Have been self-diagnosed with autism spectrum disorder

You live:
  •  In a metropolitan area of 50,000 or more people
  •  In an urban area that is a part of a larger metropolitan area
  •  In a rural area with a county population of fewer than 49,999 people and not near a larger metropolitan area

You live:
  •  In a group home
  •  In a private home
  •  Other ________

Some people and places value diversity more than others. This survey asks what these people and places are doing to support adults with autism. We want to know what an accessible community could look like in the future. Your responses can be about employment, a store, housing options, culture, or financial support. It is anything that makes you feel like a valued adult.

1. Tell me about an event or place where you have felt valued and welcomed. Describe more about your experiences.
2. Tell me what your community can do to help you feel valued and welcomed more consistently.

3. Tell me about a time when you were empowered to advocate for change. Tell me what the issue was. Your proposed change. Tell me how the issue was resolved.
# APPENDIX B: SURVEY ADVERTISEMENT

<table>
<thead>
<tr>
<th><strong>Title:</strong> Redefining Accessibility in Community Development: An Appreciative Inquiry for the 1 in 59 on the Autism Spectrum</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose:</strong> To discover what is working in communities for adults with autism spectrum disorder.</td>
</tr>
<tr>
<td><strong>Study Summary:</strong> This study uses an online survey to ask adults with autism, their families and friends what is good about neighborhoods for people with autism and what accessibility should be like for adults with autism. The survey will take approximately 30 minutes.</td>
</tr>
<tr>
<td><strong>Eligibility:</strong> Must be 21 years of age or older</td>
</tr>
<tr>
<td><strong>Study Site Location:</strong> <a href="https://tinyurl.com/y6verjvr">https://tinyurl.com/y6verjvr</a></td>
</tr>
<tr>
<td><strong>Contact Information:</strong> Anita Montgomery at <a href="mailto:anita@iastate.edu">anita@iastate.edu</a> or (870) 377-4824</td>
</tr>
</tbody>
</table>
APPENDIX C: INFORMED CONSENT FORM

Project Title: Redefining Accessibility in Community Development: An Appreciative Inquiry for the 1 in 59 on the Autism Spectrum

Investigator: Anita Montgomery, a Master of Science candidate in Community Development at Iowa State University in the College of Agriculture and Life Sciences.

We want to find out what is good about places for people with autism. We want to know what towns should be like for adults with autism. This survey should take about 30 minutes.

A research study is a way to learn more about people. If you decide that you want to be part of it, you will be asked some questions.

- First, we want to know about you. For example, we want to know if you are a person with autism, a family member, or a friend. We want to know the size of town you live in.
- Then we want to know about times when you have felt respected. How can we work toward more of those times?

This study is only for adults 21 years of age or older.
You will not have any costs for taking this survey.
We will not pay any fees for taking this survey.
Your participation is voluntary.

You do not have to answer a question if you do not want to. You may stop the survey at any time. Just close the browser window.

There will be no penalties if you decide to stop the survey.

BENEFITS and RISKS

You will not get direct benefits from taking this survey. Your responses may help us learn what we can do to help adults on the spectrum. There are no likely risks with taking this survey.

CONFIDENTIALITY

We will write a report about what we learned from the study. This report will not include your name or that you were in the study. Your answers will be stored in Qualtrics software. This is a password protected format. The data will later be stored in an encrypted, password protected cloud software.

We will not collect names or usernames. We will not collect email or IP addresses. We will not collect ZIP codes. We will remove location names from your answers. Your answers may be used in the final report after this process.

We may reach out to authorities if you report abuse, neglect or a threat of harm to yourself or others.

FUTURE USE YOUR INFORMATION
No personal data will be shared. Only the final report will be shared.

QUESTIONS

We encourage you to ask questions at any time. For questions about this study, contact the investigator Anita Montgomery at (870) 377-4824 or anita@iastate.edu. You may also contact the Responsible Faculty Dr. Timothy Borich at (515) 294-0220 or borich@iastate.edu.

For questions about your rights as research subject or a research-related injury, contact:

- the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or
- Director, (515) 294-3115,
- Office for Responsible Research, Iowa State University, Ames, Iowa 50011

ELECTRONIC CONSENT: Please select your choice below. You may print a copy of this form for your records. Clicking on the “Agree” button means:

- You have read the above information.
- You voluntarily agree to participate.
- You are 21 years of age or older.

Clicking below indicates that I have read the description of the study and I agree to participate in the study.

☐ Agree
APPENDIX D: CCF FOR AUTISM COMMUNITIES

**Human Capital:**
- Tolerance
- Leadership
- Education (of others)
- Life-long learners
- Social Programs
- Powers of attorney
- Advanced Health Directives
- Supported Decision Making
- Guardianship/Conservatorship
- 3.5 million people, their families, and friends

**Social Capital:**
- Hobbies
- Clubs
- Meet-ups
- Internships
- Volunteering
- Circles of support

**Healthy Ecosystems**

**Economic Security**

**Cultural Capital:**
- Vertical identities (where no cure is sought)
- Horizontal identities
- Siblings
- Schedules
- Routines

**Built Capital:**
- Magenta paint for crosswalks, 10’ wide
- 13’ sidewalks w/8’ walking surface
- Group Homes
- Clustered Housing
- Gated Communities
- Farmsteads
- Shared Living
- Adult Foster Care
- Tiny Homes/Accessory Dwelling Units
- Suites
- Duplexes
- Quiet Shopping Hours
- Calming Sensory Rooms
- Muted Blues and Greens Paint
- Diffused Lighting: LED or incandescent bulbs in light yellow
- Shock- and acoustically-absorbent flooring
- Discontinue “shopper experience” perfumes and essential oils
- Gender-neutral restrooms

**Political Capital:**
- None
- Measured

**Financial Capital:**
- Jobs
- Social enterprises
- Self-employment
- Micro-enterprises
- Cooperatives
- Rising Tide
- Estate Planning
- 529A
- Special Needs Trusts
- Pooled Trusts
- Life Insurance of others
APPENDIX E: IRB APPROVAL

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University according to the dates shown above. Please refer to the IRB ID number shown above in all correspondence regarding this study.

To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

- Retain signed informed consent documents for 3 years after the close of the study, when documented consent is required.

- Obtain IRB approval prior to implementing any changes to the study.

- Inform the IRB if the Principal Investigator and/or Supervising Investigator end their role or involvement with the project with sufficient time to allow an alternate PI/Supervising Investigator to assume oversight responsibility. Projects must have an eligible PI to remain open.

- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

- Stop all human subjects research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Human subjects research activity can resume once IRB approval is re-established.

- Submit an application for Continuing Review at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

IRB 03/2018