The working idea of the people associated with Uniquely the Same, Inc.

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INTRODUCTION

A Proposal Written by Those with Experience

We are Uniquely the Same - diverse, yet connected. We are composed of families and individuals affected by disability (physical, intellectual, social, sensory and others) as well as industry professionals, friends and neighbors. We each share the dignity of being made in the image of our maker as well as the struggles that are a part of the human condition. We believe we are better together than as isolated individuals.

Within this document, you will find a repeatable proposal for a network of sites within the broader community that address matters of housing, employment and other quality of life concerns. This is a living document because we are continually comparing our needs to best practice solutions. We invite you to join this effort by adding your unique perspective, experience and expertise.

Parents

Every parent thinks about their child's future. Parents prepare and assist as their children (even adult children) pursue personal aspirations. For parents of a child with special needs the concern is particularly acute. Will my child be safe? Will they lead a productive life? Who will take care of them when I am unable? Will they be happy?

Individuals

Every person longs to establish and manage their own objectives, priorities and goals. We get a sense of well-being when our needs are met, especially when they are based on a reliable foundation. Dignity is realized when Individuals can provide for themselves, as well as, bring value to others. We do not wish to be alone. We want to have friends and to be a friend to others. Even with varied social personalities, everyone wants to be an integral part of an inclusive, authentic, loving community. Will I lead a productive life? What is my place in the world? Do I matter? Who are my friends?

Quality of Life

Like everyone else, the large majority of people affected by disability are neither heroes nor people to be pitied. It is important to recognize that all people share the strengths and weaknesses of the human condition. We have individual; abilities, shortcomings, passions, fears, aspirations, and uncertainty. Our goals and hopes are as diverse as our background stories but all people deserve an adequate opportunity to pursue basic quality of life matters including; Housing, Employment, Transportation, Education and Medical Services/Care.

How Do We View Disability?

Our society has a deeply ingrained bias toward perfection. Perfection has become the measuring stick. While everyone falls short of this absurd standard, we each have learned to hide, ignore or be dishonest about shortcomings. Anything noticeably short of perfection is relegated to an opportunity to overcome. This emphasis on "personal overcoming" extends to our false view of disability.

Disability is often viewed as an abnormal part of life in a normal world. However, disability is not a defining personal characteristic. Rather, disability is the gap between capability and present demands of the circumstance. Disability is a relationship between a person and their environment. Rather than talking about disabled people, we should more often talk about disabling environments. For housing this

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means access not only to one's own house but to the houses of others. For employment, this means more than work accommodation... it means building new businesses that emphasize strength based employment, alternative management structures and creative entrepreneurial businesses. For transportation, this means more than mere accommodation and access. It means valuing and celebrating the participation of every individual in community events. For education, it means more than accommodated learning. It means self-directed personal growth and the pursuit of personal passions. For medical services and care it means more than health maintenance and filling care gaps, it means well-being and proactive health management.

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A SUMMARY of Our Idea

We seek a participatory community that authentically includes individuals and families affected by disability. <u>Our idea¹</u> is to develop multiple locations within the community which offer benefits to all citizens by pursuing innovative solutions which address the quality-of-life needs of people and families affected by disability. While we anticipate the cooperative efforts of commercial, non-profit and government organizations, our vision emphasizes approaches that seek to minimize reliance on public services and funding. With a phased approach, we will address people's needs for: housing, employment, transportation, medical services/care, education and authentic social engagement.

- 1) <u>Housing</u> We will pursue diverse residence settings with varying levels of care. Residence options include privately owned, rental, assisted living, and transition housing (for those pursuing more independence).
- 2) <u>Employment</u> The development will contain businesses that offer strength-based vocations, an employment center and a venture capital group for establishing unique business models.
- Medical Service/Care A service center will contain the offices of businesses who serve people affected by disability (i.e. doctors, therapists, agencies, educators, trainers, designers, equipment venders, DayHab/adult day services, caregivers, faith community groups, and counselors). By co-locating services:
 - a. Access is eased for those served;
 - b. A more concentrated community of consumers can insist on higher standards of care;
 - c. Services can be streamlined through better coordination among providers; and
 - d. Communication among service providers can improve.
- 4) <u>Transportation</u> The planned development will reduce the personal transportation needs of residents and serve as an accessible hub for the entire community. Transportation and ease of access will be intentionally excellent within the development. Resident participants will use private and public transportation to access the services, opportunities and social activities of the surrounding community while non-residents will have easy access to the development via the same public transportation.
- 5) <u>Education and Personal Growth</u> This planned combination of services and supports (funded commercially, privately and publicly) allows for greater access to educational opportunities, personal development, spiritual enrichment and social engagement. Every participating individual will be encouraged and supported as they pursue self-determined goals and objectives for their own growth.

<u>In order to accomplish this</u>, we are praying and looking for land, investors, realtors, developers, disability sensitive architects, other professionals, as well as individuals, caregivers and parents affected by disability.

¹ "Our idea" is constantly improving. Please help us by contacting us with your critique and ideas. If you are reading this document, we welcome your input. Send Email to <u>ida@UniquelyTheSame.org</u>.

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We are currently considering specific opportunities in the metropolitan areas surrounding: Columbia, South Carolina; Pittsburgh, Pennsylvania; Holland, Michigan; Cleveland, Ohio and Dayton, Ohio.

NOTES to consider regarding Our Idea

Notes that may be missing from the above statement:

- Rather than a "Place" where all people belong, should we say, a "Home?" a "Neighborhood?" or a "Community?"
- While public/private cooperation is essential, matters of efficiency demand that government and private domains remain autonomous.
- Housing For community services and social engagement.
- Employment Each person will be an integral part of the campus community as each participant uses their strengths to contribute to the success of others.
- Medical Services/Care The buying power of subdivision participants will enable participants to
 insist on high standards of medical service/care as well as allowing for streamlined services
 when possible. The co-location of these services allows for improved communication and
 coordination between providers as well as ease of access for those served.
- All participants (service providers and customers) will be valued such that relationships of reciprocity rather than relationships of power are the norm.
- Education
- Transportation
- Authentic Relationships are the key

MODELS that have impacted Our Idea

Primary Models that have significantly impacted our approach:

- a. Joni and Friends Family Retreats www.joniandfriends.org
- b. Kishorit (Kishor (Carmel), Israel) http://www.kishorit.org.il/en
- c. Friendship House (Western Seminary: Holland, Michigan and Duke Divinity School: Durham, NC) <u>www.westernsem.edu</u>
- d. Benjamin's Hope (Holland, Michigan) www.benjaminshope.net
- e. Bittersweet Farm (Whitehouse (Toledo), Ohio) www.bittersweetfarms.org
- f. Brookwood Community (Brookshire (Houston), TX) <u>www.brookwoodcommunity.org</u>

Secondary Models that have impacted our approach:

- a. Beverly Farm (Godfrey (St Louis), Illinois) <u>www.beverlyfarm.org</u>
- b. Echoing Hope Ranch (Hereford (Tucson), Arizona) <u>www.echoinghoperanch.org</u>
- c. Generations of Hope Development Corporation (Champaign, Illinois) www.gdhc.generationsofhope.org
- d. OSPREY Village (near Hilton Head, South Carolina) <u>www.ospreyvillage.org</u>
- e. Innisfree Village (near Charlottesville, Virginia) <u>www.innisfreevillage.org</u>
- f. Longwood at Oakmont Retirement Community (Oakmont (Pittsburgh), PA) <u>http://www.longwoodatoakmont.com</u>
- g. Sherwood Oaks Retirement Community (Cranberry (Pittsburgh), PA) http://www.sherwood-oaks.com

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- h. The Woodlands Foundation (Wexford (Pittsburgh), PA) (Spina Bifida Association of Western PA) http://mywoodlands.org
- i. Friendship Community (Lancaster, PA) <u>https://www.friendshipcommunity.net</u>
- j. Achieva (Allegheny, PA) https://www.achieva.info
- k. Christian Community Development Association (John Perkins Atlanta) https://ccda.org
- I. L'arche Communities (Erie, PA and others) http://www.larcheerie.org
- m. Jeremiah's Village (Zelienople, PA) <u>http://gladerun.org</u>
- n. Jeremiah Program 2 Generations at a Time (Minneapolis-St Paul) https://jeremiahprogram.org
- o. Summer Institute on Theology and Disability <u>http://faithanddisability.org/projects/summer-institute</u>
- p. Wright State University <u>https://www.wright.edu</u>
- q. Edinboro University of Pennsylvania <u>http://www.edinboro.edu</u>

Tertiary Models have further informed our approach:

- a. Humanitas in the Netherlands Deventer Netherlands <u>https://www.humanitas.nl/over-ons/about-humanitas</u>
- b. Bruderhof Community (Spring Valley/New Meadow Run) (Farmington (Uniontown), PA) http://www.bruderhof.com/en
- c. Bethesda Lutheran Communities <u>http://bethesdalutherancommunities.org</u>
- d. Jeremiah Village (Zelienople (Pittsburgh), PA)
- e. Milestone Hydroponic Lettuce (Pittsburgh) http://agsci.psu.edu
- f. Lamb's Farm (Libertyville, Illinois) <u>http://www.lambsfarm.org</u>
- g. Erik's Retreat (Minneapolis) <u>http://www.eriksranch.org</u>
- h. Trinity House (Bloomsburg, PA) http://www.columbiacountyhousing.com/properties/trinityhouseapartments.html
- i. Co-Ho Ecovillage (Corvallis, Oregon) <u>https://www.cohoecovillage.org</u>
- j. The Dave Wright Apartments (Heidelberg, PA) Elliott Frank (developer)
- k. Leg Up Farm (York, PA) <u>http://www.legupfarm.org</u>
- I. Sweetwater Spectrum (Sonoma, CA) http://sweetwaterspectrum.org/home0.aspx
- m. Sunflower Hill (Pleasanton, CA) <u>https://sunflowerhill.org/about-sunflower-hill/sunflower-hill-irby-ranchpleasanton</u>
- n. Innisfree Free (Crozet, VA)
- o. Villages of Noah's Landing (Lakeland, FL) / Noah's Ark Central Florida http://noahsarkflorida.org
- p. ARC Village Jacksonville, FL https://www.arcjacksonville.org/thearcvillage
- q. Bergen County United Way (BCUW) and Madeline Corporation partnership (Paramus, NJ) http://www.bergenunitedway.org/who-we-are/bcuwmadeline-partnership.php
- r. L'Arche Communities
- s. Jill's House

STATISTICS that support Our Idea

Statistics:

Disabilitycompendium.org Joniandfriends.org There are a few powerful overview statistics on the <u>www.fredconference.com</u> website.

PHRASES that we use

Uniquely the Same

• All are welcome. Each one celebrated.

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- #IamUtS I am uniquely the same. You are uniquely the same. Together, we can change the world.
- We live in a world where nothing works quite the way God designed it to work. This problem is not exclusive to those affected by disability or those who are economically disadvantaged. Some of us display our brokenness more obviously, but we are all broken people. Each of us is broken spiritually, physically, mentally, emotionally, and relationally.

... AT THE SAME TIME...

ALL people are made in God's image and have gifts that are meant to provide extraordinary value to each other, to our faith communities and to our society.

- All people are broken, we just exhibit our brokenness differently.
- Caring relationships provide the foundation for collaborative solutions which offer dignity, purpose and value through an integrated community and spiritual life.
- Quality-of-Life Needs Because of the unique circumstances of some individuals, the most fundamental components of self-actualized lives are the most difficult to obtain fundamental things like, housing, employment, transportation, education, medical resources and authentic community participation. Because of the daily grind faced by these families, they often do not have the time or energy to access these basic quality of life components.
- There is no "us" and "them". It is just "us" each of us and all of us.
- Strength based employment When it comes to quality-of-life matters (housing, employment, transportation, education, medical resources and authentic community participation), the current area that needs the most innovative solutions is that of employment. Employment statistics demonstrate that workplace accommodations only address a small percentage of circumstances. The 95% solution requires the design of new businesses which utilize the strengths of all individuals and adapt to their life needs.
- The power of partnership
- Least restrictive environment

WORDING from other organizations that we might consider

OSPREY Village (near Hilton Head, South Carolina) – Our Special People Reaching out to Elders and Youth

- People, Porches and Potential
- People Neighbors, neighborhood designed from the ground up to encourage healthy interaction for all people.
- Porches Structurally and symbolically, a front porch represents an invitation to engage with the neighborhood on a personal level. This "good old fashioned" neighborhood experience will help encourage neighbors to look out for neighbors, heart to heart and porch to porch.
- Potential At Osprey Village we want to maximize the potential for independence of those with disabilities. Conversely, it's the interconnection of a united community that provides the greatest opportunity for inclusion and empowerment. Together we can move forward.
- "Connect 'This' Ability" We seek to lessen the effects of disability by connecting our abilities together and improving all of our lives in the process.
- All parents want to be assured their children have the opportunity to live in a safe, healthy community that will enrich their lives with friendship and social interaction.

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Kishorit (Israel)

- Therapeutic Philosophy The Kishorit approach is that the therapeutic goals must be clearly
 defined and achievable, specific to the member and his/her goals and aspirations, and not to
 external standards. When a person joins Kishorit and begins the therapeutic-rehabilitative
 process, he himself defines the goals that he wants to achieve and the system tries to make it
 possible for him to do so.
- Home for life

Bookwood Community (near Houston, Texas)

•

Generations of Hope Development Corporation (Champaign, Illinois)

- Intentional neighboring 3 Core Components;
 - 1. Embracing the power of relationships
 - 2. Reframing "vulnerability"
 - 3. Older Residents are engaged in the community
- Purpose Driven Neighborhood 5 Design Patterns;
 - 1. A key focus on vulnerability
 - 2. Presence of three or more generations
 - 3. Embracing (cultivating) Diversity
 - 4. Physical design facilitates relationships
 - 5. Transformational Leadership

Building Ohana (Spokane, WA)

•

Nathaniel's Hope

•

Innisfree Village (near Charlottesville, Virginia)

• A lifesharing model of living which means that residents and their volunteer caregivers live as families in the community's 15 houses. In this close-knit environment, people develop profound relationships based on mutual needs, respect, and love.

Sweetwater Community

- Life with purpose
- A home of one's own

Jeremiah Village

•

Joni and Friends International

•

Summer Institute on Disability and Theology

•

A Place Where All People Belong¹ The working idea of the people associated with Uniquely the Same, Inc.

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EARLY DRAFT of Our Idea:

<u>Uniquely the Same's Vision</u>: A world where all people can satisfy their greatest needs regarding housing, employment, education, transportation, and medical resources. Our vision is driven by authentic, inclusive, community participation.

UtS Campus Concept: Our campus would include offices and other facilities that serve the common needs of people affected by disability. The services would include:

- 1. <u>Housing</u>: living options with varying levels of care as well as the associated food and other services necessary to provide a self-contained community.
- 2. <u>Employment</u>: a venture capital group which creates new businesses designed to serve the employment needs of people affected by disability.
- 3. <u>Transportation</u>: a reduced need for transportation due to co-location of many essential products and services on-site. A transportation center that allows people to travel to and from the campus to allow a self-determined life-style on and off campus.
- 4. <u>Education</u>: Learning and growth opportunities based on regular and intentional personal goals.
- 5. <u>Caregiving/Medical</u>: doctors, therapists, trainers, equipment vendors, counselors, and caregiving services.

Uniquely the Same's fundamental approach is to base all services on authentic, community participation.

Some principles that we think are important in order to have an excellent solution:

Shared care (and caregivers)

Participatory caregiving (applying individual strengths to bring value to others) Strength based employment

Resident Ownership

Alicia's Vision: A campus that emphasizes: 1) Christian Community (faith in Jesus, an emphasis on love for others and mutual support of one another; 2) Shared Care; and 3) Strength Based work.

Community Center Individual Living Space

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GLOSSARY of Terms, Models and Organizations

<u>Brookwood Community</u> – A Christian Community Model near Houston Texas that appears to be the most similar to that of Uniquely the Same. 112 Resident adults ("Citizens") and another 150 adults in a day program across three locations in 60 plus buildings. Brookwood also has a learning and peer networking conference 2 or 3 times a year at the Brookwood Center for Learning.

ADA – See American's with Disabilities Act

American's with Disabilities Act – Federal Legislation

UtS – Uniquely the Same

Strength Based Employment -

Least Restrictive Environment -

Congregant Living Model -

Sweetwater Housing Model – Community Support Model

CMS

Medicaid

<u>SSI</u> – Supplemental Security Income pays benefits based on financial need. SSI is administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits.

<u>SSDI</u> - Social Security Disability Insurance pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes. SSDI is administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits.

<u>The Architectural Barriers Act</u> 1968 US law required all federally owned or leased buildings to be accessible to disabled people. Among other things, it required provision of disabled-access toilet facilities.

<u>The Urban Mass Transportation Act</u> became law in 1970 - It required all new American mass transit vehicles be equipped with wheelchair lifts. Regulations were not issued until 20 years later in 1990.

<u>The (American) Rehabilitation Act of 1973</u> became law; Section 504 of the Act states "No otherwise qualified handicapped individual in the United States, shall, solely by reason of his [sic] handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." This was the first U.S. federal civil rights protection for people with disabilities. Many services are founded on this Act (for instance Centers for Independent Living). Amendments of 1986 defined supported employment as a "legitimate rehabilitation outcome."

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<u>The Education for All Handicapped Children Act</u>, PL 94-142, (renamed the Individuals with Disabilities Education Act IDEA in 1990) became law in the U.S. in 1975, and it declared that handicapped children could not be excluded from public school because of their disability, and that school districts were required to provide special services to meet the needs of handicapped children. The law also required that handicapped children be taught in a setting that resembles as closely as possible the regular school program, while also meeting their special needs.

<u>Lanterman Act</u> – 1969 California **legislation** that says **people** with **developmental disabilities** and their **families** have a **right** to get the **services** and **supports** they need to **live like people without disabilities**.

<u>The Americans with Disabilities Act</u> became law in 1990; it provided comprehensive civil rights protection for people with disabilities. Closely modeled after the Civil Rights Act and Section 504, the law was the most sweeping disability rights legislation in American history. It mandated that local, state, and federal governments and programs be accessible, that employers with more than 15 employees make "reasonable accommodations" for workers with disabilities and not discriminate against otherwise qualified workers with disabilities, and that public accommodations and commercial facilities make "reasonable modifications" to ensure access for disabled members of the public, and not discriminate against them. It also mandated provision of disabled-access toilet facilities in private buildings. The ADA also required access in public transportation and communication.

<u>The Americans with Disabilities (ADA) Amendments Act of 2008</u> became law, and it broadened the scope of who is considered disabled under the law, and when considering whether a person is disabled, the law required that people ignore the beneficial effects of any mitigating measures (except ordinary eyeglasses and contact lenses) the person uses; furthermore, when considering whether a person is substantially limited in a major life activity, which would make them disabled under the law, the law required the consideration of bodily functions as well as other major life activities, and having one major life activity substantially limited is enough; when considering whether a person whose condition is episodic or in remission is substantially limited in a major life activity, the law required the considerations as they are when the condition is in an active state; furthermore, determining someone is disabled under the law does not require individuals to meet the substantially-limited-in-a-major-life-activity standard, but does not include impairments that are transitory and minor.

<u>The Individuals with Disabilities Education Act (IDEA)</u> was the new name given in 1990 to the amended (American) Education for All Handicapped Children Act. This Act contains a permanently authorized grant program that provides federal funding to the states; all states that receive these federal funds are required to provide a "free, appropriate public education" to all children with disabilities in the "least restrictive environment."

<u>Federal Medicaid Waiver Programs</u> - Prior to 1991, the Federal Medicaid program paid for services only if a person lived in an institution. The approval of Federal Medicaid Waiver programs in 1991 allowed states to provide services to consumers in their homes and in their communities.

<u>The Help America Vote Act (HAVA)</u> became law in the U.S. in 2002, and it required voting "systems" to be accessible for all those with disabilities, including special assistance for blind or otherwise visually impaired voters.

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<u>Jonathan's Law</u> is the "popular name" of the amendments to New York Mental Hygiene Law Article 33. Jonathan's Law, a New York statute, was signed into law in May 2007; it entitles parents and legal guardians access to all child abuse investigation files and medical history records. The legislative measure is intended to hold residential mental health facilities accountable by requiring notification of guardians in cases of ill treatment, and requires written reports of ensuing investigations. Mike and Lisa Carey, the parents of Jonathan Carey, promoted Jonathan's Law. Jonathan Carey, who had severe autism, was abused and neglected at school and later killed by a direct care worker.

<u>The Genetic Information Nondiscrimination Act</u> of 2008 (Pub.L. 110–233, 122 Stat. 881, enacted May 21, 2008, GINA) became law in the U.S. The Act prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to developing a disease in the future. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions.

<u>The 21st Century Communications and Video Accessibility Act, known as CVAA</u>, was signed into law in 2010. It requires that unedited, full-length programs shown on TV with captions must also be captioned when they are made available online, with more requirements to be phased in at later dates.

<u>Service Animal Laws</u> - On March 15, 2011, new Americans with Disabilities Act rules came into effect. These rules expanded accessibility requirements for recreational facilities such as swimming pools, golf courses, exercise clubs, and boating facilities. They also set standards for the use of wheelchairs and other mobility devices like Segways in public spaces, and changed the standards for things such as selling tickets to events and reserving accessible hotel rooms. The new rules also clearly defined "service animal" as "...any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability." This portion of the law also states that the services the service animal provides must be "directly related to the handler's disability" and dogs that provide only emotional support or crime deterrence cannot be defined as service animals.

<u>The Stephen Beck, Jr. Achieving a Better Life Experience Act of 2014 (the ABLE Act)</u> was signed into law in 2014. This Act creates a new Section 529A of the Internal Revenue Service Code of 1986 to create taxfree savings accounts (ABLE accounts, also known as 529A plans) for qualified expenses. With these accounts (each person may have only one account) people with disabilities who have a condition that occurred before age 26 can save up to \$100,000 without risking eligibility for Supplemental Security Income and other government programs. They can also keep their Medicaid coverage no matter how much money they accrue in their ABLE account. Interest earned on savings will be tax-free. Under current gift-tax limitations as of 2014, as much as \$14,000 could be deposited annually. However, each state must put regulations in place so that financial institutions can make the ABLE accounts available, and there is no guarantee a particular state will do so.

<u>Legislative History of Disability in the United States</u> – See the UtS PDF Document "A Brief History of Legislation – Colorado University Resources for Disabled Students.

Fair Housing Act -

Civil Rights of Institutionalized Persons Act -