FARMING ON THE SPECTRUM
AN AUTOETHNOGRAPHIC JOURNEY TO SOCIAL FARMING

By

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ABSTRACT

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Nationally and globally dispersed, farms have been developed that focus specifically on individuals with autism spectrum disorders. This practice has been referred to as social farming, green farming or care farming. Social farming is an evolving scenario, more common in Europe than in the United States. In many cases these experiences were born autonomously, which is represented by the absence of a defined institutional framework. The current patchwork-like reality of social farming is that it developed mostly on a voluntary basis, through bottom-up actions, and not supported by any specific policies.

This research examines the motivations for social farming through autoethnographic methods of reflection and analysis. Autoethnographic research is a way of producing meaningful, accessible, and evocative research grounded in personal experiences. (Ellis, 2010) Autoethnography recognizes multiple ways of knowledge construction and embraces subjectivity. As a more accessible text, autoethnography offers to reach a wider audience that traditional research usually disregards.

This research is gathered from my own journey that starts with the diagnosis of my son with autism spectrum disorders (ASD) to opening up a farm where crops were secondary to the other benefits. This study is based on select data from 2000 – 2012 including the operation of a social farm for the summers of 2010 and 2011. This research and writing seeks to describe and systematically analyze my personal experiences in order to understand this complex issues or “wicked” problem facing families and individuals with ASD. The rising rates of autism may

make this an urgent issue, but this is also an old concern of how, as a community, we choose to live.

Social farming can also be seen as a process of social innovation where collective learning and practices are rooted in local experiences. The farming experience can lead to change by being the venue where people connect. I found that a farm has many features that may give those with ASD the opportunity to engage as well as others. The farm can give a structure that connects across boundaries and disciplines and people to begin to create a framework for inclusion. However, this is a paradigm shift away from traditional engagement and therapies for those with ASD, even at other farms. From my journey and supported in literature, there is a need for improvement in creating positive and supportive opportunities for those with ASD that recognize and respect their voice, perspective, and exceptional abilities.

At the start of this research I developed the following hypotheses:

1. Motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism.
2. Social farming fills a gap left by the lack of institutional supports.
3. As the farm is part of the surrounding rural community, social farming supports inclusion.

DEDICATION

To Joel, who always believed in me even when I didn’t believe in myself.
To Isabel, for your hugs and beautiful pictures that comforted and inspired me.
To Harry, without you I would never have imagined this journey.
Thank you ALL from the bottom of my heart.

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To my family, who rode the journey with me from thought to action and were patient as I tried to find my way. To my extended family who have helped me so much by believing in me. I know sometimes it seemed a bit unconventional and you were not sure what I was trying to do, but supported me nonetheless! To my mom who farmed along side of us and all of those who were willing to try social farming. Thank you.

PREFACE

This dissertation research is based on both my informal, personal experiences and my formal education and training. What do I really know? I know that my autistic son craves physical contact but can pull away from a hug. He sleeps under his pillows and blankets, in the bottom of a make-shift bunk bed, with curtains surrounding him, a pile of books nearby. I know he is a bumper, a wall hugger, with a hand constantly touching whatever is near as he walks by. He does not adhere to the sidewalk rules, walking just into the grass or mulch or snow. He kicks the dirt in the barn. He drags his feet. He often looks down at the ground. He fidgets with his glasses, as he is anxious. He is negative and argumentative at times, especially times of anxiety, stress, or fatigue. He drifts off of task, sometimes. He never budges from task, other times. He can get things into his head that he cannot overcome. Clumsy and uncoordinated seem like harsh words to the reality of it. He learned to ride a bike at 7.

Occupational therapy helped him gain strength and motor planning. It helped him with anxieties. It pushed him, and us. It comforted him, and us. He needed a sensory diet throughout the day to be able to function in a traditional setting. We tried to incorporate many of the techniques at home and school. We wanted to integrate his therapy into his natural daily life.
So, we bought a farm.

For the last six years, my son has been hauling hay, mucking stalls, feeding and caring for chickens and goats. He has hauled soil and compost with wheel barrels, planted corn, cucumbers (loves pickles), tomatoes, squashes, eggplants and other items. He harvested wild blackberries for jelly and picked apples too! He is connected with the land and the animals here. One counselor told me that my son was not empathetic and that empathy is very hard to teach.

However, everyday my son views the weather and makes choices to care for the animals. There is a concern and empathy for them.

After we bought the farm, we began to open it up to others. We have held farm days for those on the spectrum, for preschoolers at Spartan Development Center, and for the last two years the farm has been a Universal Farming Opportunity or UFO for those who would like to garden in an inclusive environment, sharing in both the produce and the opportunities to learn from one another. A very wise woman once told me that for people with autism to excel in life, the community has to “own our children”, they have to be integrated into the community fabric.

I wondered if the farm could do that, and more.

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CHAPTER 1

INTRODUCTION

This research is both self-reflective and inquisitive on a family's journey through the autism spectrum to a universal farming opportunity. Linking insights and knowledge to action is a large challenge (Jacobs, Garfin, & Lenart, 2005), however, this journey may provide insight that traditional positivist approaches to knowledge generation have overlooked. This research and writing seeks to describe and systematically analyze my personal experiences in order to understand this complex issue or "wicked" problem facing families and individuals with ASD. From my journey and supported in literature, there is a need for institutional support and community inclusion. There is also a need for assistance for families to be able to create positive and supportive opportunities for those with ASD. Both have to be present for success. A farm is only one method that connects across boundaries and disciplines to begin to create such a framework. The rising rates of autism may make this an urgent issue but this is also an old concern of how, as a community, we choose to live.

This research is only a slice of experience, of my experience, with navigating and living with disabilities in the family. This research is not meant to advocate the needs of one disability over any other. My experience is with autism, however, through my literature review I learned that our history is filled with the unmet needs of people with varied disabilities. I now see that my call to action of developing a social farm is wholly consistent with a recognized need to provide for those that society has so willingly forgotten and refuses to adequately fund. This research, although discovered through personal experiences with autism, illuminates issues of basic human rights.

Background of Study

There is an increasing worldwide population with autism. Autism spectrum disorder (ASD or autism) is defined as a spectrum of psychological conditions characterized by widespread abnormalities of social interactions and communication as well as severely restricted interests and highly repetitive behavior. The Centers for Disease Control and Prevention (CDC) estimates that about 1 in 88 children have been identified with an autism spectrum disorder (ASD). ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252). This new estimate marks a 23% increase since the last report in 2009, and a 78% increase since the first report in 2007 (CDC, 2012). I have a son with autism. We are part of the statistics.

After my son was diagnosed, there was a steep learning curve for my family. It was clear to me that I needed to integrate my son's therapy into his natural daily life. I saw how his therapies helped him gain strength and motor planning. They helped him with anxieties but he needed a sensory diet (heavy work) throughout the day to be able to function in everyday life. Also at a young age, my son showed more interest in animals than people. At the age of 4-5, he was able to care for his hamster "Bob". It was also at this time when my son first rode on a horse. When he was riding his horse, it seemed like it was the first time he was ever calm. It was also the first time I saw him with sustained engagement in an activity (not including sedentary activities like trains, cars and books). Horse riding also became the avenue to experience other challenges such as getting very wet while riding outside in the rain.

With a better understanding of his needs, a farm seemed like an opportunity to provide an outlet for him. So, for the last six years, my son has been hauling hay and water, mucking stalls, feeding and caring for chickens, goats, horses and a sheep. What I did not expect was that he has also showed a connection to the land. He relishes planting and caring for crops such as corn, cucumbers (he loves pickles), tomatoes, squashes, eggplants and other items. Perhaps this is a broader connection to a farming lifestyle reminiscent of agrarian ideals (Thompson, 2010).

I see this farming also as an opportunity for skill development as he grows older. Public education provides assistance and therapies and career planning for those with ASD. However, ASD does not end at age 26 when public education ends. Career opportunities can be limited and may direct individuals to more traditional positions such as janitorial work, and may not offer opportunities to connect with the land, the animals and nature. It is hoped that farming will offer therapeutic benefits, great opportunities for learning and growth in an environment filled with animals and hope.

Social Farming

We have opened our farm to others on the autistic spectrum to create a UFO or Universal Farming Opportunity. The UFO allows those with ASD and their families or caregivers to actively garden; to grow and eat fresh food; to be exposed to new vegetables and new ways of cooking; to learn about agriculture and learn to care for farm animals; and to develop their own relationship with the farm and with each other and the community. We held our first open house for the UFO and subsequent planting in June 2010.

I have realized that starting my farm for individuals with autism is not a unique phenomenon. I have identified at least 30 farms in various stages of development for those with ASD, globally. The oldest, in England, has been operating since the 1970's. However, there is little literature on motivations for starting the farms, or if they were also started by parents, or a mother, trying to meet the needs of their autistic child.

Wicked Problems

This dissertation work is not offering a cure for ASD or the suggestion that a farm fits all families. It is not meant to promote my journey over others. It is simply an attempt to integrate personal insight with literature for those with ASD in a limited way. But this small slice of insight can be combined with other insights to work on the complex issue of how to live with ASD as a family and part of a community. This is a growing issue, between the increase in diagnosis of ASD and the inconsistent health coverage to address early intervention and therapies. In 2011 only 29 states had medical insurance coverage for autism (NCLS, 2012). One of the unintended consequences with the lack of insurance for autism treatments is that States without coverage do not attract providers which reduce the overall pool of qualified professionals. In turn, it is more difficult to find providers even for a family that is willing to pay for services out-of-pocket. However, on April 18, 2012, Michigan became the 30th state to enact autism insurance reform.

Another issue facing those with ASD is a struggle for equality in the school system. Under federal mandates – including the No Child Left Behind Act and the Individuals with Disabilities Education Act – all students should succeed in the classroom. A recent research report in Michigan showed that children with ASD do not receive appropriate educational services. This has social and economic implications for those individuals and society. Undereducated adults with ASD may require taxpayer-provided supports for the rest of their lives (Bolt & Ferreri, 2011). There is also documented an overall lack of career or vocational opportunities for those with ASD. Individuals with ASD have markedly different vocational needs than individuals with other developmental disabilities (Muller, Schuler, Burton, & Yates, 2003). The uneven cognitive and social abilities associated with ASD results in a diverse set of vocational needs that are challenging to address with usual practices, create problems with employment stability, and result in isolated work opportunities. The additional needs increase these challenges associated with finding appropriate and successful employment for adults with ASD (Mawhood & Howlin, 1999). The lack of entitlements for individuals with ASD as they age out of the education system has contributed to a call to examine the utility of existing services and further expand adult services (Shattuck et al., 2007). The small body of research in this area suggests that services provided through vocational rehabilitation programs are less than optimal for individuals with ASD.

Such complex issues have been referred to in other literature as “wicked problems”. The term wicked problems is used extensively in design and software development (Churchman, 1967). According to Rittel and Melvin (1972), “wicked problems” have unique characteristics. For example, one characteristic is that a wicked problem can’t be fully defined until the solution has been found. Solutions are dependent on the state of knowledge at the time. The understanding of autism and the needs of individuals also reflects the current status of knowledge and dominant ways of thinking. Many strides in identification and diagnosis of ASD have been made by the medical community. However, more of an emergent – reflective approach that embraces various ways of knowing, including input from those with ASD and their families could shed light on issues of the entire person with ASD. This multidisciplinary or transdisciplinary approach to the production of knowledge is the integration and synthesis of many different perspectives, including different academic disciplines working with practitioners to solve real world problems (Batie, 2008). Autism is an area ripe for transdisciplinary research. It is my understanding that there are silos of information representing knowledge about autism and that these have existed despite the need for integration, or even sharing. Autism has not had a consistent home of knowledge. It has not had a consistent home for research. It has not had an integrated home for families to go to get information about ASD or treatments. Medical or academic knowledge is typically gathered, housed, and delivered in a uni-directional method, and parental, sibling, or even an individual's own knowledge is not well-valued or integrated. There are peer publications, parental books, websites, and individual books like Temple Grandin's, are all valuable sources, but because of their audience or methods, have not been integrated into the more formal body of knowledge. However, parents are experts when it comes to their children. Parents of children with autism often recognize differences about their children early (Schall, 2000). Regardless of that fact, pediatricians and other experts may assure parents that their child is fine (Maurice, Mannion, Letso, & Perry, 2001). Professionals sometimes dismiss parents as being unreliable (Schall, 2000). Nevertheless, a growing body of literature suggests that parental reports of ongoing behavior are as accurate as test results (Goin-Kochel & Myers, 2004). Hawe & Dadds (2006) compared a self-report parenting questionnaire with an observation coding system and found that research and parent self-ratings were consistent. Parents know their children, and engaging parents in collaborative research may provide them with the tools to create change (Ditrano & Silverstein, 2006).

Parents want educators to listen to them (Stoner et al., 2005). According to Harte, the dedication, knowledge, and diligence of professionals have a significant effect on the lives of children with autism, and researchers should not ignore or minimize it. The results of her study furnish evidence that parents have expert knowledge, as well as knowledge about their children. Parents of children with autism use many strategies to keep children engaged in the home setting (Harte, 2009). Incorporating various inputs are even more important when wicked problems do not have a stopping point and solutions evolve with new information.

Another characteristic of wicked problems is that the consequences count significantly. The impact of opportunities and interventions affects people's life-paths and true quality of life for those on the spectrum, their caretakers, and the community. It is a matter of judgment which ideas should be implemented. There are no set criteria for decision making and therefore decisions are not always based on equity – consideration is needed for adequate funding for health insurance coverage, long term opportunities, and other alternatives. And finally, for wicked problems - every problem is unique. There is no one-size- fits- all solution, therapy, treatment or situation. There can be both an acknowledgement to act and to develop of alternatives based on a variety of ways of knowing.

The table below describes some characteristics of wicked problems and corresponding issues in the ASD.

Table 1: Comparison of Characteristics

Characteristics of a wicked problem	**Issues facing ASD as wicked problems**
The problem can't be defined until the solution has been found.	The understanding of autism and the needs of individuals is likely to reflect the current status of knowledge and dominant way of thinking however more an emergent – reflective approach that embraces various ways of knowing is needed.
There is not a stopping point as it is the best one can do within limitations.	As ASD diagnosis becomes more prevalent, knowledge generation and an increase in the transboundary co-production of knowledge is needed that accounts for insights from those on the spectrum and their caregivers. One of the biggest limitations is within the public system.
There is no perfect solution or ultimate answer.	ASD impacts individuals, each with their own unique needs, however the impact of not acting or the promise of snake-oil solutions are also competing with sound reflective approaches.
The consequences count significantly.	The impact of opportunities and interventions affects people's life-paths and true quality of life for those on the spectrum, their caretakers, and the community.

Table-1 (cont'd)

It is a matter of judgment which ideas should be implemented. There are no set criteria.	Decisions are not always based on equity – consideration is needed for adequate funding for health insurance coverage, long term opportunities, and other alternatives.
Every problem is unique	There is no one-size fits all solution, therapy, treatment or situation but there can be both an acknowledgement to act and to develop of alternatives based on a variety of ways of knowing.

Addressing wicked problems poses a dilemma for normal science activities. Normal science is the routine work of disciplinary scientists "puzzle solving" in their paradigm. Normal science research (i.e., conventional or mainstream research) adds to the details of the established theory but does not challenge it or test its assumptions (Kuhn, 1962).

I hope that this research generates new knowledge that can lead to new plans and a higher quality of life for people with ASD. Freire demonstrated that helping individuals gain access to information and to understand the societal issues that impact their lives are fundamental tools for community change (Freire, 1973). To further the point, Freire wrote:

> Education either functions as an instrument which is used to facilitate the integration of generations into the logic of the present system and bring about conformity to it, or it becomes 'the practice of freedom', the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world. (p. 72)

Advocates for disability rights, which include parents of children with disabilities, have continued their efforts to effect change in society by engaging in social action. "We can [through social action] accomplish something which is never attainable in the natural sciences, namely the subjective understanding of the action of the component individuals" (Weber, 1968). It is through this process of education and social action that I hope to address a truly “wicked problem “and promote change.

Rationale for Qualitative Research Approach

It was during my graduate work that my son was diagnosed with autism. Working with my son highlighted the importance of seeing things differently and embracing different ways of knowing. Ironically, my knowledge regarding autism was not always respected. I was his parent, not an expert, and was dismissed in meetings at his school by teachers and school administrators. However, my voice may be of value because I have a unique standpoint. A standpoint is a place from which human beings view the world. Standpoint theory supports the notion that the perspectives of marginalized individuals can help create more objective accounts of the world (Harding, 1991). So it is my position as a mother of a son with ASD that I view the world. I have experiences and insight that are not experienced by many other members of society. I want to give this voice.

The choice of autoethnography is a non-positivist approach to this wicked problem. It allows me to understand and share my own knowledge about the autism spectrum disorder, from an insider’s perspective. Why is the experience of raising a child with autism important? Why is it worth studying and how is it relevant in today’s society? There are a number of factors that show the importance of this study including the prevalence of autism, the misconceptions about autism, the current structure of social services, the individual efforts, on a global scale, for farming opportunities for those with autism and yet the lack of current literature. I believe a more comprehensive understanding of the motivation of individuals to provide agricultural experiences to those on the autism spectrum will not only benefit parents by minimizing our marginalization but will also benefit professionals within special education and social services.

It is my hope that this research provides a framework for action. It may provide insight into a truly wicked problem.

Nationally and globally dispersed, farms have been developed that focus specifically on individuals with autism spectrum disorder. This research examines the motivations for this approach through autoethnographic methods of reflection. This research and writing seeks to describe and systematically analyze my personal experiences in order to understand this complex issue or “wicked” problem facing families with ASD. From my journey and supported in literature, there is a need for institutional support and community inclusion. There is also a need for assistance for families to be able to create positive and supportive opportunities for those with ASD. Both have to be present for success. A farm is only one method that connects across boundaries and disciplines to begin to create such a framework. The rising rates of autism may make this an urgent issue but this is also an old concern of how, as a community, we choose to live.

The research problem under investigation is to understand the process and motivations that can lead to the development of a social farm. This is documented in my own journey from diagnosis of my son with ASD to opening up a farm where crops were almost secondary to the other benefits. At the time I had not heard of the term social farming. Social farming is an evolving scenario, more common in Europe than in the United States. In many cases these experiences were born autonomously, which is represented by the absence of a defined institutional framework. The current patchwork-like reality of social farming is that it mostly developed on a voluntary basis, bottom-up actions, and not supported by any specific policies. Social farming is also known as care farming, farming for health, or green care. I believe social farming can also be seen as a process of social innovation where collective learning and practices are rooted in local experiences. The farming experience can lead to change by being the venue where people connect. The farm has a built in system that gives those with ASD the opportunity to engage and the farm gives a positive structure for others to engage, as well.

Autoethnographic research is a way of producing meaningful, accessible, and evocative research grounded in personal experiences (Ellis, 2010). My personal journey of knowledge construction and my experiences as a mother with a son with ASD can be a part of the dialogue of traditional science-based research on ASD. Therefore, this research is situated in a variety of disciplines including disability research and civic agriculture. Feminism provides a political and theoretical framework to discuss the socio-cultural image of motherhood and to question the gendered care work in families of children with autism.

Research Plan

Research Objectives:

1. To understand the journey a family takes to a universal farming opportunity where participants work the land and tend animals. This will address the perceived benefits and the larger issues facing ASD individuals that would encourage them to engage in this activity.
2. To improve knowledge about the relationship between the different ways of knowing and agriculture; to understand knowledge construction and sharing; and how farmstead opportunities can lead to improved quality of life for those with ASD.

Research Hypotheses:

I knew, or thought I knew, my motivations for the farm as well as my hopes. So, in the spirit of constructivist inquiry, the following hypotheses were developed:

1. Motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism.
2. Social farming fills a gap left by the lack of institutional supports.
3. As the farm is part of the surrounding rural community, social farming supports inclusion.

Terminology

Americans with Disability Act (ADA) of 1990: The nation's first comprehensive civil rights law for people with disabilities. The ADA makes it illegal to discriminate against anyone who has a mental or physical disability in the area of employment, public services, transportation, public accommodations and telecommunications.

Autism Spectrum Disorder (ASD): This is a range of neurological disorders that most markedly involve some degree of difficulty with communication and interpersonal relationships, as well as obsessions and repetitive behaviors. As the term "spectrum" indicates, there can be a wide range of effects. Those at the lower-functioning end of the spectrum may be profoundly unable to break out of their own world and may be described as having Kanner's autism. Those at the higher-functioning end, sometimes diagnosed with Asperger Syndrome (AS), may be able to lead independent lives but still be awkward in their social interactions

Center for Disease Control (CDC): The US agency charged with tracking and investigating public health trends. The stated mission of the CDC is "To promote health and quality of life by preventing and controlling disease, injury, and disability." The CDC is a part of the U.S. Public Health Services (PHS) under the Department of Health and Human Services (HHS).

Community Supported Agriculture (CSA): It is an alternative, locally-based socio-economic model of agriculture and food distribution. A CSA also refers to a particular network or association of individuals who have pledged to support one or more local farms, with growers and consumers sharing the risks and benefits of food production**.**

Individuals with Disabilities Act (IDEA): A United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. It addresses the educational needs of children with disabilities from birth to age 18 or 21 in cases that involve 14 specified categories of disability. IDEA was originally enacted by Congress in 1975 to ensure that children with disabilities have the opportunity to receive a free appropriate public education, just like other children.

National Institute of Health (NIH): Federal agency whose mission is to improve the health of the people of the United States. NIH is a part of the Public Health Service, which is part of the U.S. Department of Health and Human Services.

Universal Farming Opportunity (UFO): Similar to CSA but a further commitment to inclusion. Inclusion means that all people should freely, openly and without pity accommodate any person with a disability without restrictions or limitations of any kind,

What's Ahead?

The remainder of this qualitative dissertation follows this path. Chapter 2 presents research literature reviewed to frame this research endeavor. Chapter 3 discusses in some detail the methodological approach utilized in the collection of data and the scholarly precedents for such an approach. Chapter 4 is a summary of my journey and corresponding data. Chapter 5 is the analysis and identification of common themes. Chapter 6 provides conclusions based upon the research undertaken and presents actionable recommendations in support of the research's initial intention of providing key data for this and others to consider. Chapter 7 is a reflective essay on this process by this researcher.

CHAPTER 2

LITERATURE REVIEW

The research problem under investigation in this autoethnographic case study is to understand how a family with a son with autism spectrum disorder (ASD) realizes the need for a Universal Farming Opportunity and learns from the experience by opening their doors to others. This research looks at how social farming may provide insight into a wicked problem faced in society – understanding and listening to the needs for those with ASD and giving those with ASD rights and opportunities to actively participate in their communities. The explicit purpose of this study is to increase the dialogue surrounding social farming and documenting insight for further research.

Literature for this research includes an overview of autism including material that is produced by other parents with children with ASD and individuals with ASD. Academic and (traditionally known as) non-academic material is used to inform this research. This literature review also gives an overview on social farming with emphasis on farmsteads for those with ASD. There is very little literature on social farms in the United States although there has been a history of farms for those with disabilities. A short US historical research is performed to provide insight into this checkered past. The literature review also covers my own ontology and change in world view because of my position as a mother with a son on the spectrum, an academic and an engineer.

Autism Spectrum Disorders (ASD)

Autism spectrum disorders (ASDs) are a group of developmental disabilities characterized by atypical development in socialization, communication and behavior. ASDs are typically apparent before the age of 3 years with impairments affecting multiple areas of a person's life (CDC, 2009). ASDs continue to be conditions of urgent public health concern affecting approximately 1% of children in the United States. ASDs affect an average of 1 in every 110 children: approximately 1 in 70 boys and 1 in 310 girls. The prevalence of ASDs increased from 2002 to 2006 (CDC, 2009). Some recent population based studies have documented even higher ASD prevalence estimates of >1% of children in areas of Japan, Sweden, the United Kingdom , and the United States (Baird, 2006; Baron-Cohen, 2009; Honda, 2005; Kadesjo, 1999). Autism incidence shows no sign yet of plateauing. Younger ages at diagnosis, differential migration, changes in diagnostic criteria, and the inclusion of milder cases do not fully explain the observed increases (Hertz-Picciotto & Delwiche, 2009). Researchers (Kabot, Masi, & Segal, 2003) believe that ASDs originate from a combination of genetic, neurological and environmental factors.

Autism was first officially diagnosed by two psychiatrists, Leo Kanner and Hans Asperger that had published articles in the 1940's that identified infantile autism as a distinct syndrome (Sicile-Kira, 2004). Prior to this research, children with these symptoms who were brought to the attention of the medical profession were seen either as severely deprived of social stimuli or chronically insane. The earliest scientific theories blamed mothers for their children's condition; the most notable example was Bruno Bettelheim's theory of the refrigerator mother (Sicile-Kira, 2004). Bernard Rimland has been credited in giving new insight into autism as a psychologist and father of a son with ASD. He dispelled the refrigerator mother syndrome as the cause of autism, instead promoting a biological disorder (Rimland, 1964).

Autism spectrum disorders (ASD) and Asperger's syndrome have been recognized by psychiatrists as a Diagnostic and Statistical Manual of Mental Disorders (DSM) category and by other medical professionals, including neurologists, as a condition of significance for brain research (Volkmar, Klin, & Cohen,1997). The DSM manual evolved from systems for collecting census and psychiatric hospital statistics, and from a manual developed by the US Army. It was first published in 1952 and has been revised multiple times. According to the DSM IV criterion, ASDs are usually evident in the first five years of life. ASD typically manifests in children before age three, whereas Asperger's has a later onset (e.g. when the child is five or six years of age). Myles and Simpson (1998) state that ASD has been identified throughout the world, among all racial, ethnic, economic and social groups. Common characteristics include severe and pervasive impairment in reciprocal social skills, communication skills, and in the presence of stereotyped, restricted, and repetitive interests and activities (APA, 1994). There may be abnormalities in cognitive skills and co-occurring medial conditions, such as central nervous system abnormalities. Children with ASD may also exhibit behavioral symptoms, such as impulsivity, aggressiveness, hyperactivity, and attention problems. They may experience sensory problems (high tolerance for pain, over/under sensitively to touch, sounds, or odors, and be "picky eaters"). They may also exhibit sleep problems (Attwood, 1998).

Diagnosis

According to Waltz (2002), screening for ASD can begin in several ways. A child may be referred for screening by a parent, childcare worker, school official, or pediatrician. Often the first person to become aware of parents' concern regarding their child is the pediatrician. However the pediatrician may not recognize the early signs of ASD and may reassure parents that children develop at their own pace. Ideally, a multidisciplinary team should do the screening with an expert in ASD as part of the team. Parents provide a developmental and family history. Assessment should include a medical, vision and hearing test. An audiological evaluation is crucial because children with central auditory processing problems often exhibit communication, attention and social problems. Diagnoses should never be based on a single test (Waltz 2002).

Attwood, a practicing clinical psychologist, provides assistance with diagnosis and strategies for those with ASD, specifically Asperger's. Attwood claims that at the time of writing (1998), there was little knowledge about both diagnosis and treatment for those with Asperger's. Also, at the time of the book, the mean age of diagnosis was 8 years old.

Treatment and Therapies

From the 1960s through the 1970s, research into treatments for autism focused on medications such as LSD, electric shock, and behavior change techniques. The latter relied on pain and punishment. It was not until 1980 that autism became an official clinical diagnosis, separate from childhood schizophrenia or retardation. Since that time, as scientists have learned more, they have broadened the diagnosis to include a spectrum of disabilities. (Newsweek, 2006) Dr. Thomas Insel, NIMH states that "families have become the real experts on this disorder. They have to figure out how to cope with a child who becomes explosive, disruptive, who could have a meltdown at any moment. They become highly skilled at knowing what helps." (Kantrowitz & Scelfo, 2006) During the 1980s and 1990s, the role of behavior therapy and the use of highly controlled learning environments emerged as the primary treatments for many forms of autism and related conditions. Currently, the cornerstone of autism therapy is behavior therapy. Other treatments are added as needed. The characteristics of effective interventions outlined by the Committee on Educational Interventions for Children with Autism (Lord & McGee, 2001), stated that programs should focus on early intervention, intensive instructional programming, with the specific inclusion of the parents in the treatment process. Early intervention has been reported to enhance these outcomes, as well as decrease the probability of restrictive placements later in life (Handlemann & Harris, 2000).

There is a growing recognition that programming that integrates various approaches, such as discrete trial and applied behavioral analysis and developmentally oriented approaches, such as Floor Time provides the greatest benefits (Greenspan & Weider, 1998). Greenspan discusses an integrated approach to therapy using a floor-time model. Floor time is a “systematic way of working with a child to help him climb the development ladder”. Basically, floor time uses an integrated approach: parents do floor time; other providers such as speech and language use floor time principles; parents work on their own responses to maximize their interactions and create a family pattern (Greenspan & Weider, 1998). In a study by Dionne, the floor time therapy research did indicate a significant difference between the numbers of circles of communication during the intervention phase as compared with the observation phase and therefore provides preliminary evidence for the use of the FTP approach with a child with autism (2011). These therapies, coupled with techniques for enhancing functional communication through both verbal language training and alternative modes of communication, show the greatest likelihood for overall positive outcomes. (Wetherby, Prizant & Hutchinson, 1998)

Occupational Therapy

Children and adolescents with ASD need a range of interventions. For young children with ASD, occupational therapists focus on enhancing children’s sensory processing, sensory-motor performance, social-behavioral performance, self-care and participation in play. In older children, OT may focus on social and behavioral performance, transition to work and independence in the community (Case-Smith, 2008). Within the field of occupational therapy, one of the most commonly used frameworks for treating autism is sensory integration theory, developed by Dr. A. Jean Ayers, (Ayers, 1972) Children with autism were more affected by sensory abnormalities than were children with language impairment and developmental disability (Leekam, 2007). Unusual responses to sensory stimuli are seen in many children with autism (Kranowitz, 1998; Rogers 2005).

Sensory integration intervention appears to enhance the child's ability to modulate behavior and participate in social interactions. (Baranek, 2002) Sensory integration therapy has been successful for those with ASD. Statistically significant differences between groups indicated that the sensory integration therapy program positively affected treated children (Fazlioglu, 2008). However, the causes and effects of specific sensory information processing abnormalities in children diagnosed with autism constitute a fruitful field for further investigation (Gerrard, 2009).

Jackson discusses how ASD impacts his life including his own fascinations and sensory issues, sleep and eating. He discusses therapies such as different diets and Taekwondo. He also covers strategies that have worked specifically for him including dating, understanding literal translations. Jackson, wrote the book as a 13 year old with Aspergers although claims "I'm not an expert" (Jackson, 2003).

Speech and Language Therapy

Children with ASD frequently have various kinds of language deficits. In spite of these deficits, more than half of all children with ASD show an intact ability to perceive and produce speech sounds, and do develop some level of functional speech (Wetherby, Prizant & Hutchinson, 1998). Therefore, providing effective intervention to develop communication skills and language in children with ASD by utilizing their intact capacity is a high priority in efforts to treat ASD (Wetherby, Prizant & Hutchinson, 1998).

Speech and language pathologists (SLPs) are collaborators in a diagnostic process that reflects an increasing number of referrals of children with autism spectrums disorders (ASD). The speech-language pathologist's ability to imagine and respect what others may be thinking or feeling is inherent in all aspects of assessment and intervention. Nowhere is this perspective more important than when working with children with autism spectrum disorder (ASD) and their families (Diehl, 2003). Research shows the need to develop an assessment reference binder for all SLPs and the development of a standardized assessment process.

Music therapy has also been successful with people with ASD. Results showed that participants in both music and speech training significantly increased their pre to posttest verbal production (Lim, 2010).

Sometimes SLPs or through other organizations, work with those with ASD also can benefit from Social Skills (Coucouvanis, 2005). Social skills training uses visuals, games, and role playing to discuss and learn societal acceptable responses in social situations. Social development of children with autism is often measured in terms of their progress toward acquiring normal social skills (Coucouvanis, 2005). Since autism is a form of bodily difference that interferes with the person’s ability to process information (sensory, language, tactile, and visual) in a typical fashion, children learn to cope by either imitating norms of behavior or making sense of the world within their unique perceptual systems (Nikopoulos & Keenan, 2004). In this regard, normalization is often seen as a powerful tool for the remediation of the effects of autism. Simply “acting normal” is a form of adaptation and is even hypothesized as conducive to brain development.

Animal-Assisted Therapy

Therapeutic opportunities for those with autism are diverse and have included a dog that is trained to keep a child with autism from running away in public, or a dolphin inspiring a child with autism to say their first words, or a horse who helps a child with autism to initiate appropriate social behaviors. It is becoming more commonplace to hear about the relationship between animals and autism. Temple Grandin has been the ambassador for both. (Grandin & Johnson, 2009)

In Animal-assisted therapy (AAT) an animal with specific characteristics is chosen to become a fundamental part of a person's treatment. The presence of the animal, for example a horse, a dog, or a cat can improve social and emotional functioning of the patient and provide some motivation for the patient to participate in the treatment. As Levinson stated: "Frequently, a pet is the only remaining link with reality." (Levinson, p. 27), providing a self-object experience (Alper, 1993). Thus, the animal provides a sense of connectedness, a vital bond.

Weiss (2002) conducted a study of animal-assisted therapy and children with autism spectrum disorder. The goal of the study was to find out if animal assisted therapy could increase social interactions and spontaneous speech in children diagnosed with autism. Weiss did not record any numerical data from the first session, since the purpose was to see how the girl behaves in a typical situation. During the second session (no dog), the girl produced 63 occurrences of spontaneous speech and 51 attempts at social interaction. The third session (dog present) showed an increase in both social interactions (185) and spontaneous speech (261). Though not as frequent as the third session, the fourth session (dog present) also showed an increase in social interactions (153) and spontaneous speech (168) from the second session with no dog present. Weiss explains that the day before the fourth session, her dog suffered a broken foot and was not as willing to be interactive with the girl. Overall, the sessions with a dog present resulted in more social interactions and more occurrences of spontaneous speech. When with the dog, the girl was able to express feelings of happiness, talked with and about the dog, played with the dog, and related the play activities to movies and stories from her prior knowledge. “All of these positive behaviors are areas where autistic children tend to show greatest deficits” (Weiss, 2002).

These data support the hypotheses that children with autism would demonstrate significantly more social interactions and would make significantly more frequent use of language in sessions incorporating animals than in sessions exclusively using standard occupational therapy techniques. These findings are consistent with recent research suggesting that enhancing children's motivation to become active partners in the therapeutic process results in greater treatment gains. As opposed to being rewarded for engaging in a therapeutic activity by being presented with a reinforcer that is unrelated to the task, the children were able to engage in therapeutic activities where the reward was intrinsic to the activity itself. Further, and consistent with the philosophy of the widely used sensory integration approach, all of these elements of therapy took place in a naturalistic environment, in that the animals responded spontaneously and genuinely to the children's behaviors (Fortney, Sams, & Willenbring, 2006). One study of the use of ants used in a therapy session was beneficial because the characteristics of these animals would help the individual with ASD bond without pressure. He could then regulate his interest at his own pace (Topel & Lachmann, 2008).

Anderson (2007) agrees that dogs help bring out positive behavior in children with disabilities in the empirical study of having a dog in a classroom including students with emotional and behavioral disorders. The outcomes of the study were that students’ attitudes toward school improved, they found companionship with the dog, and students learned self-regulation by “managing their behaviors toward the dog through appropriate verbal and physical interactions” (Anderson, 2007). Also, the frequency of positive peer interactions in the classroom increased, which supports Weiss’ research. Other research results suggest that the children demonstrated significantly greater use of language and significantly greater social interaction in sessions incorporating animals when compared to sessions using exclusively standard occupational therapy techniques (Forntney, Sams, & Willenbring, 2006). There has been only one study with farm animals. Berget found that AAT with farm animals may have positive influences on self-efficacy and coping ability among psychiatric patients with long lasting psychiatric symptoms (2008).

Hippotherapy or therapeutic horse riding was shown to be one alternative therapy that improved deficits in autistic children. By controlling the movements of the horse, it is hypothesized that individuals should gain muscle strength, balance, and improved posture. Research suggests that hippotherapy also improves speech, language, and cognitive functioning. Dismuke-Blakely (2009) suggested that it is the enhanced sensory integration and arousal systems that enable a child to be more receptive to speech and language therapy.

Other Approaches to Therapy

As the ASD population grows, more ideas are identified. Other therapies include diet and exercise; plant therapy; as well as medical interventions (drugs) (NIH, 2007). School therapies are also evolving including the use of a MSE or multi-sensory environment (MSE) for children with disabilities. MSE rooms have shown an increase in skills and some evidence of generalization of those skills. There was a range of disabilities in this study and there were no specific findings per disability. However, all participants, regardless of age, increased skill levels and during the study, those engaged in the MSE room exhibited joy and happiness which is important in skill development and the continuation of learning (Houghton et al., 1998).

Social Farming

Innovative and yet based in tradition, social farming is connecting both multifunctional agriculture and community-based social and health care. Known by different phrases, social farming or care farming or farming for health or green care are used interchangeably to describe agriculture for social purposes. Food production prevails at these farms and/ or the initiatives are provided by those with agricultural expertise. This does not include times when plants and animals are used mainly for therapeutic purposes by therapists in a non-farm setting (Di Iacovo & O'Connor, 2009). Green care links aspects of the traditional healthcare systems to agriculture (care farming), gardening (healing gardens), landscape or nature conservation (ecotherapy), animal keeping or animal husbandry. Green care creates a link between sectors that were not formerly linked, and can create new benefits for all sectors involved (Haubenhofer, 2010). The creation of care farms to promote physical and mental health is also a method to link societal needs to opportunities for farmers to increase their income. Many European farmers have seen the possibilities of this linkage, as the number of care farms has increased (Elings & Hassink, 2006)

The products at these farms include saleable produce, health and employment, education or therapy. .These farms offer openings for the socially disadvantaged, for young offenders, for those with learning disabilities, people with drug dependencies, the long-term unemployed, active senior citizens, and school aged children (Di Iacovo & O'Connor, 2009). Di Iacovo has documented four different stages of development for social farming: pioneer (where there are relatively few examples of social farming and is characterized by voluntary action rooted in a strong motivation);multifunctional agriculture (where the interest comes mainly from agriculture and there are local initiatives but a low level of awareness in the public); system in social/health care (where there is a strong level of interest in the health care sector and there is engagement by public institutions; inclusive model (where there are a large number of initiatives and that they have organized themselves into regional and national networks).

As with the different stages, the numbers of care farms per country differs considerably. The Netherlands is leading the way with approximately 1,000 green care farms; in Belgium, Norway, Italy, and Austria a few hundred are already established, with numbers increasing. In the United Kingdom, there are at least 80, and in Slovenia, Sweden, and Finland, the phenomenon has just started to develop (Haubenhofer, 2010). In North American, care farms are just starting to develop.

In the United States, Bittersweet Farms has been a great example of social farming. Bittersweet Farms, a community for autistic adults in northwest Ohio, was created out of the experience of teachers and parents of autistic children and adolescents (Kay, 1990). Like many of the farms for those with ASD, Bittersweet Farms is in a rural setting and uses natural contexts for residential, vocational and recreational experiences, and focuses on communication, and involvement with the larger community beyond the site (Gidden, 1993). Today, there are at least 30 different farms (globally) that identify themselves as specific for those with ASD.

History of Poor Farms in the US

There is a long history of people with disabilities connected to farms and it is not completely positive.. In the past, people with disabilities were often grouped with the poorest people, the elderly, and the ill or orphaned, and placed in a poorhouse or a poor farm house. Prior to the poorhouses, the problem of what to do with this group of people included seeking relief from the Overseer of the Poor for food, fuel, clothing, or even permission to get medical treatment to be paid out of tax funds; auctioning to the lowest bidder; or contracting with someone in the community to care. In some cases local communities had already discovered that a place to house this population helped reduce the cost. These small town poorhouses were the prototypes for the later state-required county poorhouses. Those earlier poorhouses often instituted the use of an adjacent farm on which people could work to raise their own food, thus making the houses more self-sufficient (relying less on local tax funds). That is how the term "poor farm" came into being.

During the second quarter of the 19th century, as the industrial revolution had its effect on the United States, the importation of the factory system from England was followed almost immediately by the full scale adoption of what seemed to be an inherent component of that system -- the Poorhouse System. These poorhouses were built with great optimism. They promised to be a much more efficient and cheaper way to provide relief. And there was a fervent popular belief that housing such people in institutions would provide the opportunity to reform them and cure them of the bad habits and character defects. However, mid-century, people were beginning to question the success of the poorhouse movement. Investigations were launched to examine the conditions in poorhouses. But the concern for "the bottom line" might result in the person being denied adequate food, or safe and comfortable shelter, or even necessary medical treatment. And there often was very little recourse for protection against abuse. They had proven to be much more expensive than had been anticipated.

The poorhouse population was even more narrowly defined during the twentieth century when social welfare legislation began to provide a rudimentary “safety net” for people. Eventually the poorhouses evolved almost exclusively into nursing homes for dependent elderly people. But poorhouses left orphanages, general hospitals and mental hospitals -- for which they had provided the prototype -- as their heritage (Katz, 1986).

During the mid-20th Century, health services for seriously mentally ill individuals were almost exclusively provided in large, often Victorian, institutions. Some institutions also incorporated flowers and gardens and later farms. Dr Munson was a believer in the “beauty is therapy” philosophy. Patients were treated through kindness, comfort, pleasure, and beautiful flowers provided year-round by the asylum's own greenhouses and the variety of trees Munson planted on the grounds. Restraints, such as the straitjacket, were forbidden. Also, as part of the “work is therapy” philosophy, the asylum provided opportunities for patients to gain a sense of purpose through farming, furniture construction, fruit canning, and other trades that kept the institution fully self-sufficient (Asylum Projects, 2012).

Since that time, there has been wide recognition that psychiatric institutions are unacceptable places to care for and treat persons with mental illness, being prohibitively costly, isolating and neglectful, and sometimes abusive and punitive. Civil rights advocates in the 1960s, in an unlikely alliance with fiscal conservatives, fought to close these institutions. The activists believed that persons with mental illness have rights and should be integrated in the community. They reformed mental health laws to establish more rigorous standards and procedures for compulsory admission, and litigated to close antiquated institutions. Around the same time, fiscal conservatives felt that psychiatric institutions were too expensive.

During the mid-to-late 20th Century, however, many of these old institutions were closed as part of a social compact with mentally ill persons and their families to provide community care. The deinstitutionalization movement, however, resulted in new places of confinement for this population, such as jails, prisons and homeless shelters. Some programs have been created in urban environments incorporating group homes, supervised apartments, and job coaches in work settings. In more rural areas, the farmstead model has been pioneered, offering both residential and vocational opportunities.

Motivations for Social Farming

The motivations for social farming are diverse. They can include a direct respond to the needs of particular disadvantaged groups (Di Iacovo & O’Connor, 2009). Social farming has been predominately documented in Europe since the 1960’s after the closing of psychiatric institutions and at that time there was a gap in services and opportunities for those with mental illness.

Perhaps these farmsteads are a response to the normalization movement either a promotion of the normalization movement where the farmstead continues to pursue the applied behavior analysis program (ABA) (Sicile-Kira, 2004) or as a rejection of normalization where those with ASD are free from the outside community and can experience life with those most similar to themselves.

The farmstead can also be an outlet for skill development and a response to the lack of vocational opportunities for those with ASD.

In a community, there are those that avoid people with ASD whom they perceive to be antisocial, gender inappropriate, or simply odd (Bumiller, 2008). A qualitative study of parents’ children with ASD found that parents struggled and fought to remove the isolation and to be able to protect their child with autism from a world that was not always there to support them (Woodgate, 2008). Although there are antidiscrimination principles, they provide an inadequate basis for the large-scale provision of services and educational opportunities for people with autism (O’Brien, 2005). In this frame of safety, another reason for the farmstead approach may be a harken back to the institutional movement where individuals with disabilities were separated from the community. The farmstead, in this case, does not push for inclusion but for separation.

A farm can also be an alternative to the intensification of agriculture; (Di Iacovo & O'Connor, 2009) Social farms may also meet a need for more sustainable systems of agricultural production to meet the changing needs of society (Veldkamp, 2008). The change in agriculture has been from smaller to larger farms, the decrease in ownership, and much more uniform in crop choices (Steingraber, 1998). From this change, there is movement toward more local or organic food choices.

A social farm can also be a response related to social justice and solidarity (putting personal values and beliefs into practice) (Di Iacovo & O'Connor, 2009). Social farming has developed on a voluntary basis in the form of a "bottom-up" approach unsupported by any specific policies and or institutional framework. Social farming can be seen as a process of social innovation where collective learning and practices rooted in local experiences are producing a process of change and affecting policies at various government levels.

Farms may offer an inclusive model for the caregiver as well as those with ASD. The idea that it is not only the family member with ASD that needs care, but the caregiver as well is an important point (Gillian, 1995). The right to supported caregiving would mean that the single mother would be guaranteed a level of material, financial support, of in-kind assistance, and of help with caregiving itself, so as to assure that she can provide adequate care without endangering herself and her dependents. Farmsteads may provide a community inclusive model that acknowledges this need.

These farms may fill a gap. Some farmsteads, including my own, were started by mothers caring for those on the spectrum and become motivated to act outside themselves.

Kittay and Feder refer to these women as “crusaders”. These are the parents who continue to work for disabled children and adults even when the needs for their own children are met (Kittay & Feder, 2002). This can be driven by policies that exacerbate the burden on women who are caregivers. Many states did not allow insurance coverage for autism therapies. Access to care is limited for racial and ethnic minority families, with low parental education, living in nonmetropolitan areas, and not following a major treatment approach. Disparities in service use associated with race, residence and education point to the need to develop policy, practice and family-level interventions that can address barriers to services for children with ASD (Thomas, 2007). Without those alternatives, parents may take it upon themselves to develop solutions for those with ASD.

A social farm may be a part of personal/family/community life-style choices (e.g. initiatives strongly based on ideals/ideological values) (Di Iacovo & O’Connor, 2009). Agrianism could inspire people to develop the farmstead for those with ASD. It is a model of inclusion within a strong community, growing together, where farming is a focal practice (Thompson, 2009). It is this connection to the land and to the people that is a return to agrarian ideals and a way to have meaningful encounters and a higher quality of life.

Another life-style choice is the Community Supported Agriculture (CSA) movement. Since CSAs came to the U.S. in 1986 there has been a considerable flood in food awareness and concern for the growing practices, distribution and consumption patterns inherent in industrialized agriculture. These food movements encompass a number of important environmental, economic and social concerns. Some of the many food movements include: organic food production, food safety concerns, local food, and community food security, along with an increase in urban agriculture initiatives. Care farming could become a new movement.

These movements have in common the a need for critique, reform and even a re-visioning of farming practices; exploring organic alternatives; and meeting the challenges of agriculture, health and community (Pollan, 2010).

A CSA allows for more connection to one another at a more personal and local level than has been the trend post 1940. In our case the CSA is currently referred to as a UFO. It is an inclusion (universal) farming opportunity where those that participate get a share of what is grown. Even more so that in community supported agriculture, there is a shared sense of reconnecting with others who grow our food and other like-minded individuals who want to support a community and regional economy. This type of arrangement could increase a sense of togetherness and appreciation for each other, the land and the food it produces.

A social farm can be a place where the overall personal wish to carry out (alternative) professional practice in this field (e.g. initiatives started by professional operators in the social/care/educational sectors) (Di Iacovo & O’Connor, 2009). A farmstead for those with ASD may be more about sustainable land use or the movement for local and organic foods. Food choices have long been associated with ASD – from the promise of the gluten-free diet, the sensory issues with foods (textures and tastes), the increased bowel issues, and the push towards health food choices.

A social farm may provide the opportunity to have new possible sources of incomes and/ or the wish to open up to local community (e.g. initiatives started by agricultural businesses). (Di Iacovo & O’Connor, 2009). Perhaps in Europe there was an increasing consensus that social services in rural areas could play an active role in rural development processes in order to improve local livelihoods and support economic viability (Di Iacovo & O’Connor, 2009). Through the Rural Development Programme for England, social/care farming was supported to provide opportunities for the diversification and modernization of farming through new income streams that provide a “benefit to the local community”. Waveney Valley uses care farming as a diversification priority with the potential to develop a cluster of care farms and the potential for a co-operative of care farmers to share resources, learning and experiences. In 2010 the European Network for rural development sponsored a thematic network on social farming to identify practical examples of Care Farming projects, raise awareness and share learning (Robinson, 2011).

Social Farming Research

As social farms continue to grow in European countries, documentation of the types and goals of these farms are becoming available. A report by on policies for social farms in Europe was available in 2009 (Di Iacovo & O’Connor, 2009). Case study reports (Elings & Hassink, 2008) have stated positive effects of social farming on the physical health, sense of freedom, and integration into society by their participants. Data was collected by many of the service providers at the farms. The report Green Care by the European Science Foundation was developed by scientists to discuss the principles of green care and connection with other disciplines (2010). The book provides an overview of green care approaches, different services by country, and perceptions.

There is a lack of both quantitative and qualitative research analyzing the effects of care farms on client groups. Some research has been conducted on the influence of nature on the well-being of humans but few studies deal with care farming as a particular intervention (Haubenhofer, 2010).

Case studies such as in Suffolk state that Care Farming has evidence of positive outcomes: it supports individual’s ability to develop confidence, employment skills and peer support. Care Farming has a community bases and benefits the local economy by supporting rural economies.

Van den Berg (2010) did a study for those with comparing a natural environment and a built setting for children with Attention Deficit Hyperactivity Disorder (ADHD). Two groups of six children (age 9–17) who stayed at care farms for children with ADHD in the Netherlands were systematically observed, questioned, and tested during visits to a wooded area and a small town. Both groups performed better on a concentration task in the woods than in the town, despite the fact that all children visited the town after the woods and thus their scores in the town were possibly inflated by learning effects. However, the behavior and emotional functioning in the two settings differed between the groups. One group of children liked the woods better than the town and displayed more positive behaviors and feelings in the natural environment. The other group of children liked the town equally well as the woods and displayed positive behaviors and feelings in both settings, although they showed somewhat more non-social, aggressive, inattentive, impulsive and hyperactive behavior in the town than in the woods. These results suggest that natural areas provide a consistent positive environment for children with ADHD. However, more research is needed to obtain a fuller understanding of the influences of the physical environment on children with ADHD.

Hassink identified characteristics associated with care farms that are relevant for three different client groups: clients with severe mental health problems, clients from youth care backgrounds, and frail elderly clients. She interviewed 41 clients, 33 care farmers, and 27 health professionals. The study shows that care farms are experienced as unique services because of a combination of different types of characteristic qualities: the personal and involved attitude of the farmer, a safe community, useful and diverse activities, and a green environment. This leads to an informal context that is close to normal life. Care farms can be considered as an innovative example of community-based services that can improve the quality of life of clients (Hassink,2010).

Benefits for a farm for those with ASD include long term security, safety, meaningful work, congenial associates (Gidden, 1993). Other perceived benefits of care farms are improved physical, mental, and social well-being. Mental health benefits consist of improved self-esteem, improved well-being, and improvement in mood. Examples of social benefits are independence, formation of work habits and the development of personal responsibility and social skills (Elings and Hassink, 2008; Hine et al., 2008). Patients with dementia attending day care on farms have been shown to have fewer behavioral problems, greater levels of activity and fewer drug requirements. It has been reported that care farms achieve this by incorporating a range of meaningful values such as security, structure, routine, contact with plants and animals, and diverse range of activities (Schols & Van Schriek van meel, 2006).

Ellings performed focus groups interviews with 42 people with a psychiatric or addiction history who work on eight different green care farms. Green care farms provide an opportunity for a useful occupation activity for different kinds of client groups and are a growing phenomenon in the Netherlands. In general, participants start at green care farms without concrete expectations; most of them are looking for a useful way of spending their day. Once working on a farm, they especially come to appreciate the social aspects such as belonging to a group, feeling at ease and informality. In addition, they also appreciate the space and being involved in useful activities. Undertaking farming activities helps participants feel useful and healthier and they develop more self-esteem, self-respect and responsibility. Working on a green care farm can contribute more structure and discipline to the lives of participants, which can create the foundation for new activities or (voluntary) work elsewhere (2008).

However, as farmers become involved in a new sector (care), specific questions emerge: Farmers are interested to learn how their care farm differs from traditional institutions that are providing care to people and whether their activities indeed result in an improvement of physical, mental and social well-being of clients (Hassink et al. 2002; 2007; Haubenhofer et al. 2008). On the other hand, many other stakeholders (e.g. the Ministries of Health and Agriculture, traditional care institutions and insurance companies) are interested in the contribution of green-care farms to the health sector (Hassink & Van Dijk, 2006). Because various actors are interested, research on this topic has to be multidisciplinary and participatory in order to ensure maximum benefit for society (Van de Fliert & Braun, 2002).

Another challenge for green care is for research in the field to be accepted by the scientific community. Researchers need to find new methodological approaches, or amend the current methodologies, to deliver robust, statistically significant quantitative and qualitative results to underline the positive effects of green care interventions. In doing this, professionals and policy makers in health and social care can be convinced that green care is a care approach to be taken seriously (Haubenhofer, 2010).

Knowledge Construction

This section reviews literature that attempts to understand my own motivation and journey includes my ontology and change in world view and my unique standpoint as a mother of a son with ASD. I had to shift away from a positivist philosophy and toward a more reflective and active dialogue that embraced many forms of knowledge. Historically, academic research was built under a postitivists epistemology where only scientific knowledge had value (Fischer, 2000; Schon, 1983). Auguste Comte expresses the three principal doctrines of positivism. First, there was the conviction that empirical science was not just a form of knowledge but the only source of positive knowledge of the world. Second, there was the intention to cleanse men's mind of mysticism, superstition and other forms of pseudo-knowledge. And finally, there was the program of extending scientific knowledge and technical control to human society. In postitivist epistemology of practice, craft and artistry had no lasting place in rigorous practical knowledge (Schon, 1983).

Research was institutionally separated from practice. Researchers, considered superior, were supposed to provide the basic and applied science for diagnosing and solving problems of practice. Practitioners were supposed to furnish researchers with problems for study (Schon, 1983). Knowledge had hierarchy – researchers with science on the top, professional and scholarly knowledge of the general practitioners in the middle and opinions of the public at the bottom. Being a researcher had come to mean being in a university, holding a faculty appointment, writing a certain style understood by one's peers, and conforming to an academic rewards system that encourages disengagement. Researchers believe in objectivity. Typically researchers have a difficult time conveying their work to the public. They often embrace an expert mode – conveying facts in such a manner that miss the impact on people and their own processing (Axinn, 1997). They are often more concerned with bringing people "in-line" with the experts (Thompson, 1999).

I had to learn to embrace many ways of knowing and types of knowledge. As outlined in Habermas, there are three domains of knowledge: technical knowledge using empirical or analytical methods for research (common is physics or chemistry); practical knowledge using interpretive research methods (commonly in the social sciences; and emancipatory domain which identifies self –reflection using critical theory methods (Habermas, 1984). This approach acknowledges self-reflection and has common components with feminist research: it has reflexivity, an action orientation and attention to the affective components to research and the use of the situation at hand. This approach is not dependent on the categories of established theory and technique, but constructs a new theory of the unique case and does not separate thinking from doing (Schon, 1983).

This approach also utilizes and promotes an integrated approach that combines both academic and practical approaches for double-loop learning (Argyris, 1976; Cooper, 2000). Single-loop learning is when learning is incremental compared to double-loop learning in which the learner becomes aware of the assumptions and values and is capable of rethinking in a way that reveals the limitations of their assumptions and theories, in turn driving the resolution of practical problems (Tabara, 2007).

There is a need to place discoveries in a larger context and create more interdisciplinary conversations. This is the scholarship of sharing knowledge. Reflective practitioners – moving from theory to practice and from practice back to theory –are integral for co-production and dissemination of knowledge. (Aeberhard & Rist, 2009)

Gender

Feminism provides a political and theoretical framework to discuss the socio-cultural image of motherhood and to question the gendered care work in families of children with autism. Glenn (1994) argues that mothering is closely connected with gender, not because of women's biological characteristics, but because of stratification and hierarchy within a society that devalues women and children. Mothers who have children with autism play a major caregiving role not because they are biologically more suited for the job, but because they live in a society where the division of care work is hierarchical.

The role of gender extends beyond mother and caregiver. Bumiller describes how feminist disability studies open up a broad schema for social action, promoting full inclusion of people who possess a wide range of human differences (2008). Feminist disability studies provides a forum for advocating this view of a political and social order capable of sustaining diversity and citizenship outside of the norm. The neurodiversity movement linked hormonal effects on brain development to autistic disorders (Baron-Cohen, 2003). He concluded that gender has everything to do with autism because autism is just an extreme male brain (hardwired for building systems) and that the female brain is predominantly hardwired for empathy.

Antidiscrimination principles provide an inadequate basis for the large-scale provision of services and educational opportunities for people with autism (O'Brien, 2005).   Historically, individuals with disabilities have been called disabled, retarded, or crippled, terms that diminish their personhood and highlight their impairments (Murphy, 1995; Whyte & Ingstad, 1995). Many typical citizens resist inclusion of people with autism to avoid exposure to uncomfortable interactions with people whom they perceive to be antisocial, gender inappropriate, or simply odd. More serious obstacles to inclusion result from the failure to support the high costs of treatment programs and the perceived threat of autistic people as dangerous. The responsibility of assuring disabled peoples' place in society goes far beyond the commitment to preserving individual rights; it necessitates a broader agenda as formulated by feminist disability studies. A more expansive model of inclusion needs to counteract the pull toward normalization and stake a claim about the harmful effects of devaluing all kinds of diversities, including those relating to gender, sexuality, and race (Baglieri & Knopf, 2004). Moreover, it involves challenging a de facto scheme of social exclusion created by a diminishing welfare state and the provision of fewer resources for supporting people with disabilities (Baker, 2004).

Power and Gender and Caregivers

There are complex and dynamic links between gender relations and autism. These connections exist from the many postulated causes of ASD, to the implementation of the treatment and therapies, and to the mainstream policies. The absence of a gender perspective may be in part to a lack of evidence and information but it may also be the inability of society to get over the "refrigerator mother" as the primary cause of autism.

The mainstream discourse is stereotypically masculine – with a discussion and approach to autism from the medical establishment using neurological testing and the use of MRI to detect areas in the brain that may be impacted by ASD. Main stream policy is masculine because it is housed in the medical field which has traditionally been a strong supporter of science. There has been a dismissive approach to women as caregivers, especially to those with children with ASD because of the perception that one of the original "causes" of autism was a "refrigerator mothers". Therefore the medical establishment hypothesized that inappropriate or "cold" mothering caused ASD. Since that time, caregivers have continued to be the target as the cause of ASD from their authority to choose vaccinations or the lack of breastfeeding. Research has hypothesized that moms cause autism by their mothering style or their placement of their child in harm. The medical establishment and researchers did not present women as agents capable of contributing to solutions and make broad generalizations the lump together all women

Current policies exacerbate the burden on women who are caregivers. Many states, including Michigan, do not allow insurance coverage for autism therapies. Access to care is limited for racial and ethnic minority families, with low parental education, living in nonmetropolitan areas, and not following a major treatment approach. Disparities in service use associated with race, residence and education point to the need to develop policy, practice and family-level interventions that can address barriers to services for children with ASD (Thomas, 2007). The right to supported caregiving would mean that the single mother would be guaranteed a level of material, financial support, of in-kind assistance, and of help with caregiving itself, so as to assure that she can provide adequate care without endangering herself and her dependants (West, p.111). Mothers caring for those with ASD that become motivated to act outside themselves are called “crusaders”. These are the parents who continue to work for disabled children and adults even when the needs for their own children are met.

The discussion of autism and gender and society has grown through the feminist disability literature. This scholarship has ‘unsettled how feminists conceptualize gender, sexuality, genetic and reproductive issues, and the role of women as caretakers” (Bumiller, 2008). It has renewed interest in the question of how to promote diversity and to further a more inclusive society.

CHAPTER 3

RESEARCH METHODS

This is a qualitative research study on the motivation of individuals to provide agricultural experiences to those on the autism spectrum. Qualitative research is defined as "a form of systematic empirical inquiry into meaning" (Shank, 2002). Denzin and Lincoln (2000) claim that qualitative research involves an *interpretive and naturalistic* approach: "This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them".

This research on wicked problems acknowledges that knowledge is subjective – based on the perspective of those involved and that "knowledge does not exist outside the perceiver" (Kincheloe & McLaren, 2000). It follows a constructionist research paradigm. (Guba & Lincoln, 2005). It disagrees with positivism which promotes only the voice of an objective researcher whereas constructivism may use mixed voices, reflexivity, and through the discovery and rectifying of societal problems, moves people to action (Kincheloe & McLaren, 2000). Positivists and post-positivists consider action "the domain of communities" and that even the taint of action will interfere or negate the objectivity that is a characteristic of scientific inquiry (Guba & Lincoln, 2005). However, this research embraces the human experience and seeks to capture those elements or insights that make life conflicting and problematic (Ellis & Bochner, 2000; Richardson, 2000).

I understand that because research project starts from "one's own experience", it does go against the traditional research paradigm that the researcher be detached, objective and value neutral (Reinharz, 1992). I embrace multiple voices and multiple ways of knowing (Thorpe, 2009). In fact, this research is very reminiscent of feminist research where this new “voice” is a break from the male-dominated tradition of confrontational debate (Reinharz, 1992). As a feminist researcher, I work on the border of or outside my field. As “connected knower” I live in two worlds. This ability to connect different disciplines may also reflect the general sense of connectiveness (Gilligan, 1995).

This research was conducted using autoethnography (Ellis & Bochner, 2000) as the primary research method. I choose autoethnography because this approach connects the “personal with the cultural.” It combines cultural analysis and interpretation with narrative details. It follows the anthropologic and social scientific inquiry approach (Chang, 2008). Ellis and Bochner (2000) define autoethnography as “autobiographies that self-consciously explore the interplay of the introspective, personally engaged self with cultural descriptions mediated through languages, history and ethnographic explanations.” It is a place where social scientists can “examine the contradictions they experience” (Ellis & Bochner, 2000). For my personal journey, the real work of autoethnography began when “you think you can’t stand the pain anymore.” Connecting the personal to the cultural did involve emotional pain. I did not expect to be a part of the ASD community. It was painful. It some ways, it continues to be so.

Writing autoethnography is more than writing a narrative inquiry or memoir. It is a study of “researcher’s own people”. It is a rigorous ethnographic, broadly qualitative research method that attempts to achieve in-depth cultural understanding of self and others (Chang, 2008).

Personal topics fit autoethnography inquiries well because researchers have direct access to intimate information and can investigate the subjects in depth (Chang, 2008). For my research this was especially useful because many of the documents were medical notes or report cards, conferences, emails, personal journal entries or materials I developed for teaching about Harry.

Through this data combination, I can dig deeper, excavate rich details, bring them onto examination tables to sort, label, interconnect and contextualize in the sociocultural environment (Chang, 2008).

As I explored this path and its cultural analysis and interpretation, my personal and societal descriptions will be more than just a narrative text. It should “do more than awaken moral sensibilities. It must move the other and the self to action” (Denzin, 1997). This is another great benefit for autoethnography. It has the potential to transform self and others to motivate them to work toward a cross-cultural coalition building (Chang, 2008). When researchers do autoethnography, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity (Ellis, 2010).

There are also known detriments to autoethnography. Autoethnography has been criticized as being narcissistic or self-indulgent (Holt, 2003; Salzman, 2002; Sparks, 2002). There may be a question of academic rigor or validity and subjectivity. For an autoethnographer, questions of reliability refer to the narrator's credibility. Could the narrator have had the experiences described, given available "factual evidence"? Does the narrator believe that this is actually what happened to her or him? For autoethnographers, validity means that a work evokes in readers a feeling that the experience described is lifelike, believable, and possible, a feeling that what has been represented could be true (Ellis, 2010).

For this research, data for my journey incorporated documents, journal entries written in the time of the incident, as well as email correspondences. These very factual and in the moment artifacts were used to support my reflexive writing. This combination of external document and personal journal entries addresses both with reliability and validity. This research was also compared with literature as another method of validation. However, in some areas, little research literature existed. The lack of documented theory prior to the research does not challenge the validity but in fact may offer a fresh approach (Maykut, 1994).

By using autoethnography and producing accessible texts, I may be able to reach a wider and more diverse audience than traditional research usually disregards, a move that can make personal and social change possible for more people (Ellis, 2010).

Design of Study

The design of this study consists of an autoethnography approach to understanding farming and autism from a gendered perspective. This will include the following data samples:

1. Review of personal "in the moment" writings, medical reports, school reports, presentations I developed over time for an MSU college course, photos, email correspondences, and any other documentation from 2000- 2011 starting with the birth of my son, through the development and running of a social farm.
2. Iterative and reflexive writing on my journey that is supported by data listed above.
3. A review of the literature and an attempt to overlay my reflexive writing with document and place them into context of the literature.
4. Identify my standpoint and discuss how that impacts my understanding of my journey and also place that into the context of feminist literature. This may include reflecting on the process of discovery and coping with a son with ASD in the context of being a woman, a mother and an academic.
5. Develop new and emerging ideas that were unknown at the start of this research.

6. Simply answer the original research questions based on the combination of datasets. I knew, or thought I knew, my motivations for the farm as well as my hopes. So, in the spirit of constructivist inquiry, the following hypotheses were developed:
    - Motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism.
    - Social farming fills a gap left by the lack of institutional supports.
    - As the farm is part of the surrounding rural community, social farming supports inclusion.

CHAPTER 4

DATA

This section of the dissertation is a description of my journey from the birth of my son Harry, through his diagnosis, therapies, and our purchasing and running a farm. It also includes my own philosophical transition and process of engaging not only to my family, but to my community. I write selectively but include “writings in the moment”. These writing I had captured, were not intended as part of a published document, but as personal journal entries. These writings and letters happened before I could even imagine this dissertation.   I used these writings, documents, pictures, and presentations that I had developed for classes, as anchors to my reflective writings about my experiences. These experiences were assembled using hindsight (Ellis, 2010).“Stories are the way humans make sense of the world” (Ellis, 2004). I wanted to write this story to help others understand this experience, and for those in similar situations, offer the benefit of experiencing how I had felt and acted, so they may be able to compare to their own experiences.

I hope that my personal experiencesare meaningful but also are accessible to a wider and more diverse audience that traditional research usually disregards, a move that can make personal and social change possible for more people (Bochner, 1997; Ellis, 1995).The journey is presented chronologically.

The Journey

On May 30, 2000 my son was born. He was 6 weeks early which, by definition, means he was born premature. He was my second pregnancy.

In my first pregnancy, I miscarried in the 10th week. I remember when the cramping started. We were driving home from South Dakota, where we had gone to a friend’s wedding.

At the wedding, everyone was excited for me. My husband, Joel, and I were beaming – “no drinks for us; we were expecting”. We had done everything right: we were not drinking coffee; I was eating organic foods; Joel was making sweet potato fries in the oven for snacks. We had the book “What to Expect When You’re Expecting”, but also pregnancy cook books and the monthly magazine “Mothering”. I spent my time on the internet looking for information on natural childbirth, organic cloth diapers, and breast feeding. I was not reading about miscarriages. I was not prepared. We were not prepared.

The day I arrived home, I called my doctor about the cramping. He said there was not anything we could do; if it was going to happen, we could not prevent it. I went to work. When I got out of my white Jeep, a co-worker called across the parking lot commenting how late I was coming in. I said “Fuck you”. That hurt my annual evaluation.

Despite my misplaced aggression and my extreme vocal faux pas, miscarriages are silent. It was not until I had a miscarriage that other women began to tell me about theirs. It was a club of uncommon proportions. Many miscarriages are never counted. From the American Pregnancy Association, there are approximately 6 million pregnancies every year throughout the United States:

4,058,000 live births
1,995,840 pregnancy losses

Pregnancy Losses:
600,000 women experience pregnancy loss through miscarriage
1,200,000 women experience pregnancy loss through termination
64,000 women experience pregnancy loss through ectopic pregnancy
6,000 women experience pregnancy loss through molar pregnancies
26,000 women experience pregnancy loss through stillbirth

The medical information states that women might not even know they are pregnant when they miscarry. After five pregnancies and two live births, I can say the medical profession never ceases to amaze me. I always knew I was pregnant, and that was common opinion among women. They also always knew they were miscarrying. I knew too, every time. I wondered if my former work life with chemical hazards and pathogens negatively impacted my ability to carry a pregnancy to term.

This second pregnancy was crazy scary. But then Harry was born. He was beautiful. It took a day to name him Henry but a week to name him Wallace Szymecko. Yes, he has my last name. He has his mother's last name. Whatever would be in store for him, he will have to be able to handle that.

He was a boy, from a premature birth, with an analytical father and (maybe) a 'refrigerator mother' so Harry did not stand a chance. He was diagnosed with autism at age 4.

Diagnosis

Previous research has demonstrated that children who receive early intensive behavioral intervention have a better prognosis than those who do not receive services. It is for this reason that assessments designed specifically for early identification of ASD are of paramount important (Matson, 2009).

Harry was not diagnosed by the pediatrician. In his annual checkups, he was somewhat slow to meet milestones but he was also born prematurely and we were told that he would "catch up".

On his 2nd birthday party, we made cubes that told his favorite things. Since his 2nd birthday theme was Elmo, which he liked very much, many Elmo related items are in the #1 spot.

Table 2: Top Ten for Harry at Age 2

Ranking	**Favorite Foods**	**Favorite Phrases**	**Makes me Laugh**	**Inside fun**	**Makes me Mad**	**Favorite Books**
10	Raisin toast	Knock knock. Who is it?	Family	Ride spring horse	Waiting to go outside	Where the Wild Things Are
9	Raisins	Oh, Mur-phy	Music and dancing	Ride bicycle	Empty glass	When the Relatives Came
8	Apples / bananas / blueberries	I hear a train / chuggachugga woo woo	Tent tunnels	Push lawnmower	Closed Ziploc bags with food inside	Train Book
7	Oatmeal	Knock it off!	Balls	Draw and paint	Strangers	Sheep in a Jeep
6	Kasha	Are you talking to me?	Trains	Train table	Closed doors, especially the bathroom	Runaway Bunny
5	Chicken	May I have more soy, please?	Puppets	Cook	Church	Peterson's Guide to Birds
4	Cheese	No, thank you	Sliding	Play with animals	Car rides	My First Animal Book
3	Peas/green beans	How 'bout momma?	Murphy – talking	Read books	Diaper changes	Mickey and the Morning Cake
2	Soy milk	Read-a-book	Running	Play with cars	Veggie burgers	Little Bear
1	Yogurt	Where's Elmo?	Tickle me Elmo	Play with Elmo	Where's Elmo	Elmo's Big Word Book

My observations from the list some nine years later are that Harry was (and still is) a very healthy eater, preferring more simple foods to processed foods. Eating healthy was a combination of his personal likes, his propensity for intestinal issues, and our ability to pay for and support healthy food choices. Harry was also verbal. Although the table lists favorite phrases, he did prefer to speak using familiar and often-repeated phrases (some from old movies such as “are you talking to me”!) He was very active, like most toddlers, and liked to laugh. He did enjoy playing alone and his play often consisted of setting up his figures (cars, trains, or animals). He enjoyed all aspects of trains – reading, playing, talking about them. Harry did have difficulty at transitions and did not like crowds. He loved books. He would carry and look at them over and over, every day. He would repeat information from the book “Peterson’s Guide to Birds”.

Although Harry was not diagnosed until age 4, reflecting back, I can see potential indicators of autistic behavior. There are a variety of checklists that have been developed for parents and practitioners. (Robins,2006; Murray, 2011) Based on those checklists and Harry’s documented preferences at age 2, I can identify his strong preference for solo activities; his difficulty with transitions; and his love of all things trains as potential indicators for autism.

Although work has been done using home movies for early diagnosis of autism (Palomo 2006) there has not been work on reviewing family photos. However, I have taken hundreds of photos - almost daily - of Harry in his first few years. Photos do show how he played – as a setter-upper with little Matchbox cars lined in rows; or stuffed animals strategically placed throughout a room; or dinosaurs arranged in ecosystems. Photos also show his excessive oral motor (tongue chewing) as he placed the cars just so. The photos also captured his left arm in a windmill position as he walked. I remember that well. In a gait somewhere between ‘walking’ and ‘running’, Harry would make complete arm circles with his left arm. It was quite a sight. He also would flap with both arms at times of frustration. However, I do not have pictures of him flapping both arms. It is my guess that those times were hard to record because I was in the process of consoling and engaging and hoping to prevent any further meltdown. There are also pictures of Harry carefully holding Bob, his hamster, on his lap. At the time, Harry knew that Bob was not doing well, but Harry was trying to provide some comfort. There are pictures of Harry as a toddler, running with a frisbee as Murphy, our border collie, gently grabs at it. There is such a huge smile on Harry's face in those photos that his eyes look like little crescent moons. There is a also a picture my brother took of a small infant, with eyes shut tight, wrapped in the hospital-issue white blanket, lying in an incubator in the Neonatal Intensive Care Unit at Sparrow Hospital. This picture is a reminder of how far Harry has come and how much he had overcome.

Before Harry was diagnosed, I learned to maneuver around situations that were not particularly helpful for Harry. Sometimes that was difficult, such as when the situation was a family children's birthday party. I remember a particular party well, because it was in a nice apartment about 80 miles from home. Harry was 3 years old, and I also took my daughter, who was 3 months old. Joel had to work and I never thought twice about going without him.

The party was typical for a 4-year-old guest of honor, with decorations and cake and games. Then, at one point, Harry was in the only bathroom in the apartment, screaming. He was just standing in this little pink tiled bathroom screaming at the top of his lungs. I was on my knees with him, the door closed, trying to console him. I was crying too, not because of his screams, but what this really meant. I felt like something was wrong. Poor, poor Harry. Something was so very wrong and I didn't know what to do. I quietly calmed him down by telling him. "It's ok, Harry. It's going to be ok" over and over. Maybe I was just telling it to myself. I had to come out of the bathroom with Harry, my eyes were red, but I remember smiling to the group saying, "Oh, he is ok. Just too much excitement". As the party continued and the focus returned to the honored guest, Harry was ok. He had a book, he calmed down. We finished up with the party and I drove the three of us back home. I remember it felt like a very long ride even though both kids slept all the way home.

Our path to a formal diagnosis started in October 2004 and went through to the Spring 2005. Harry was attending Spartan Child Development Center (SCDC). SCDC was an inclusive day care that was located next to Michigan State University. It was at his fall evaluation that his teacher told me that Harry was "unique". I remember nodding in agreement and went home. It was only late that night that I began to wonder if being "unique" had other meanings. The next day I asked his teacher what she meant. She was very kind and stated that she was not diagnosing but wondered if he would be a candidate for evaluation through the Keeping Early Education Positive program (KEEP) at the State of Michigan Department of Community Health. She also recommended a book on sensory integration. She explained that if I agreed, someone from the KEEP program (who does this all the time), would walk me through the process and it would take place at the center while Harry was in daycare. We would learn about Harry and his needs. I left the center, nodding in agreement and open to what we would learn. However, I remember crying so hard as I told Joel that something may be wrong. He was very calm and wanted to know exactly what they had said.

That evening I picked up the book "Out of Sync Child" (Kranowitz, 1998). I was at the mall with my sister (by my parent's house). I told her that I had to pick up a book – it wasn't until I found it that I could say it out loud. I told her that it was recommended by his preschool teacher. I was probably crying. I just know that I poured over the contents. The book itself had a checklist.

I recorded at that time Harry had displayed the following symptoms from the list:

Arm flapper
Poor eye contact

Seeks physical contact
Loves to be tickled
Poor balance
Poor manual skills
Uses extraneous movement during physical activity
Fails to follow verbal directions
Loves spicy food

Later, I remember my sister telling me she picked up the same book.

The KEEP program contacted me to start the process and explained that they worked in multiple steps, which , in some ways, had its advantages. It allowed Joel and I to learn and cope. However, the long timeline for a diagnosis made me anxious for not really knowing. The KEEP program provided short-term child/family-centered consultation for children with challenging behaviors (according to their website). Someone came to Harry's class for observation. She recommended additional evaluations for him – an occupational therapist and a speech and language therapist. These were referred to as initial screenings. They may or may not recommend further evaluations. Harry's screenings always did.

One of the hardest parts of this process was trying to cope. I coped by talking. I talked to everyone who would listen including my siblings, my parents, my co-workers, my friends, and the lady at the department store. I had a single-subject focus and I could only talk about Harry. My husband also was coping, but in a very different way. He chose to research and read and withdraw. He did not discuss Harry's process with family or co-workers or friends. It took 8 months for him to tell his mother. I would like to think we talked about it between ourselves, but I bet I did most of the talking. The hardest part for both of us was the unknown.

This was particularly hard over the winter holidays. I remember Joel's mom took Harry to a family function. Joel had not told her anything. Afterwards, she said that Harry was just fine. I was so relieved. I was worried about him going but Joel reassured me. About a month later, someone who was at that party told me that Harry was “out of control” and that she had to sit him down. I was heart-broken. I knew but didn’t want to know. To me it was just Harry. He was a loving and beautiful little boy. When we were driving, he would say to me “momma’s hand?’ and I would reach my arm into the back seat and he would hold it and he would suck his thumb and tilt his head to lean against the headrest of his car seat and close his eyes. He always wanted someone’s hand to hold. If I as busy driving – he would say “how about daddy”?

Then it was Christmas. Harry was 4 and Izzy was 1 years old. We were all staying at my mom and dad’s house in a suburb of Detroit. It is a nice 3 bedroom ranch built in the 1950’s. My parents were in their bedroom, we (Joel, Harry and I, Isabel and our dog) had one bedroom and my sister and her family (including 2 older boys) was in the third bedroom. I remember being so very anxious about Harry. At this point, I knew “something was wrong” but I didn’t know what it was. It did not have a name. I was trying to protect Harry, perhaps, but I was really just protecting myself. Looking back, I was very protective of him but maybe of me too and our family. I remember yelling at my sister at some point. I do not remember what I said. I just remember screaming something at the top of my lungs from my bedroom to hers. That was a tough holiday.

That spring we met with a neuropsychologist. After extensive testing, the results were a diagnosis of PDD-NOS / Aspergers. Then, I went to see Dr B., a pediatric psychologist. This is the letter I wrote when I waited for Harry in the waiting room of his office.

> Although I spent the whole night on the web reading, I became so engrossed with my homework assignment (that was due yesterday) that we were almost late.
>
> Arriving at the building - the scores of common looking brick medical stripmalls, I could not remember which one-although I was there one day before. I had to turn around in the corresponding apartment complex parking lot, over a snow bank, almost side-swiping a car leaving the apartments (they could never guess what a hazard their location was).

When we were going over the snow bank, Harry asked if we were going to the doctors. “Well, no, you’re not sick” I said though I thought, what should I tell him? B. is a doctor. “We are seeing a psychiatrist, a sort-of doctor”. I said.

“What does he do?” Harry asked.

“He listens to people”, I said. I have such a knot in my chest as I pull to the parking lot.

“Why does he listen to people?” Harry asks

“To learn about them, what they like”. I said as I got out of the car.

Opening Harry’s door, he asked “Can I take my elephant?”

“Sure.” I said smiling through tears.

“Are you going to come with me?”

“No, I am going to wait for you and do my homework and when you are done, we will meet dad for lunch”.

We wait in the waiting room and I notice his hair is feathering up. I try to wet it down. I just can’t remember which side is his part on. We read a book as I fuss over his hair.

“Do you want me to look good?” Harry asks.

“You look great! I just can’t remember how to part your hair!” I said, realizing my fussing needed to stop, but it was hard to stop pushing his hair off of his forehead.

The door opened with Dr. B.. He doesn’t make eye contact with me. Strange. I smile. He introduces himself to Harry. He asks about his elephant.
“Well, what do you have there”?

“It is a stuffed animal, an elephant”. Harry replies.

“Does he have a name?” asks the doctor as he escorts him out of the room.

“No” Harry says

I think back to the checklist or was it on the internet –“unable to pretend – difficultly with naming an object different from the physical appearance of that object’.

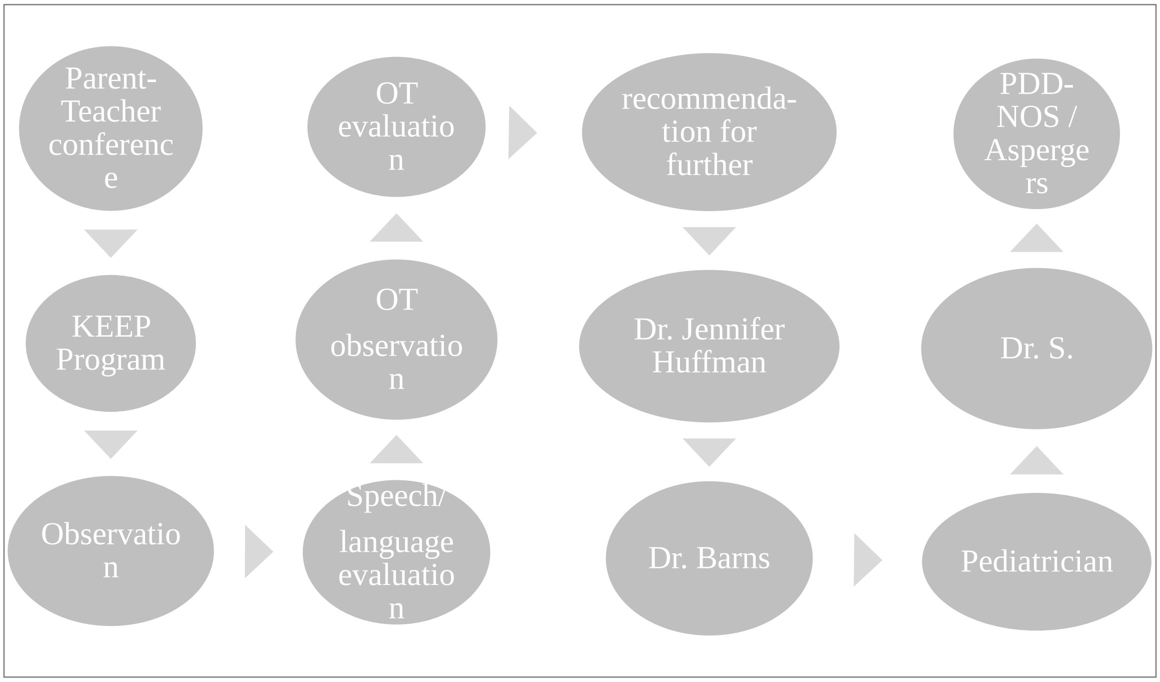
“Well, maybe we can give him one today.” Dr. B. says.

I hope so.

Diagnosis Timing

The figure below shows the many steps that started in October and ended the following summer. It was a painful process. I had little child development knowledge. I did not know anyone with autism and I had never heard of PPD-NOS. Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is a 'subthreshold' condition in which some - but not all - features of autism are identified. (APA, 1994) It is included in DSM-IV where there are marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest, but when full features for autism or another explicitly defined PDD are not met. Harry’s diagnosis also specified “traits of aspergers”. Asperger's Syndrome is defined as showing deficits in social interaction and unusual responses to the environment, similar to those symptoms present in autism. Unlike in autism, cognitive and communicative development are within the normal or near-normal range in the first years of life, and verbal skills are usually an area of relative strength. Idiosyncratic interests are common and may take the form of an unusual and/or highly circumscribed interests (e.g., in train schedules, snakes, the weather, deep-fry cookers, or telegraph pole insulators).

Figure 1: Path to Diagnosis



Like any mother, I looked for more information either from books or the web. From the Asperger's Syndrome a Guide for Parents and Professionals by Attwood, Harry displayed the other symptoms similar to AS:

Avoids social play
Does not understand social code of conduct
Unusual qualities to conversation
Fascination with particular topic
Clumsiness
Disruptive or aggressive

Now that we had the diagnosis, we had to figure out what we were going to do about it. His diagnosis did not come from his pediatrician. I was at a loss as to where to find services to help him. I went to the Employee Assistance center at Michigan State University. I wondered if they had any recommendations. The counselor asked about how I was doing and how Joel was doing. Surprised, I said that I was there for resource assistance. He explained how families grieve over such a diagnosis. That I had a loss. That surely I (and Joel) had expectations for our son and that those expectations may not be met. I needed to allow myself to grieve so that I could be open to whomever Harry was going to be – his independent self. Stunned, I left his office. I went to the computer to read about parents of kids with special needs and on-line I found the poem “Welcome to Holland” by Emily Perl Kingsley (1987).

> I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this….
>
> When you’re going to have a baby, it’s like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum.The Michelangelo David.The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.
>
> After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”
>
> “Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”
>
> But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.
>
> The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place.
>
> So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.
>
> It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a whole and you catch your breath, you look around…and you begin to notice that Holland has windmills…and Holland has tulips. Holland even has Rembrandts.
>
> But everyone you know is busy coming and going from Italy…and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say “Yes, that‘s where I was supposed to go. That’s what I had planned’”
>
> And the pain of that will never, ever, ever, ever go away…because the loss of that dream is a very very significant loss.

> But…if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things…about Holland.

Even reading that poem today still chokes me up. I am forever grateful for Harry and the way he has taught me to see things differently and to embrace our own differences. I think by being open to letting Harry define himself, he was able to build his self-esteem. He does not view autism as "bad", just different. I don't either.

Therapies

Early intervention for Harry included occupational therapy (OT), play therapy and behavioral therapy and speech and language therapy (speech) for articulation and pragmatics. We also tried music therapy and hippotherapy and social skills groups. We worked through private therapists and the local school system. Most expenses were out of pocket. There are a wide range of options and philosophies for autism therapies. OT and speech were recommended by KEEP and typical therapies for our diagnosis. Dr. S was an autism consultant recommended by our pediatrician. Harry's pediatrician gave us the pamphlet for Dr. S's practice. Through working at MSU, I had heard about music therapy and signed Harry up for that. On a road we travelled to get to campus, there is a billboard for therapeutic horse riding or hippotherapy. During one of Harry's OT sessions, I saw a brochure for hippotherapy on the corkboard. I told his therapist that I was thinking about horse therapy. She said I should check into it. At home that evening, I tried to find that number from the program on the billboard without any luck, but I did find a number for CHUM Therapeutic Riding. Harry still rides there today.

Occupational Therapy and Sensory Integration

Harry began occupational therapy (OT) for fine and gross motor skills and for sensory integration. I remember the sessions for Harry – they usually started with some gross motor work – scooter down a slide; bouncing; then maybe catching a weighted ball while bouncing or swinging on his stomach. He then did some fine motor work like using tweezers to pick up small objects, and then he would practice writing. Harry wrote his letters differently – he wanted to start at the bottom of a letter and write upwards, ending at the top of the letter. He also wanted to write from right to left (bottom to top). Needless to say, this created a lot of frustration. The session usually ended with something he regarded as “fun” to do, such as a game or a swing he liked. We went to therapy every week from the time Harry was 5 (the summer before kindergarten) until he was 7 (end of first grade) and we still use many of the principles today.

Some of the work with Harry was to help with sensory processing. Sensory integration (SI) dysfunction is the inability to process information received through the senses. Often misunderstood, SI dysfunction influences learning, movement, relating to others, and feelings. The causes are unknown. SI dysfunction may impact some or all senses, such as touch (tactile); balance and movement (vestibular/proprioceptive); coordination; muscle tone; hearing (auditory); sight (visual); smell (olfactory); as well as attention and behavior. Harry’s occupational therapist recommended a sensory diet. This is a family-centered approach of providing sensory integrative therapy to meet the needs of a specific child and family. Sensory diets include activities that help with the feeling of calm, alert, and in an "optimal" state of arousal. Planned, scheduled activities are imbedded throughout the day and include the input and support of parents, teachers, and any others with whom the person may be in contact.

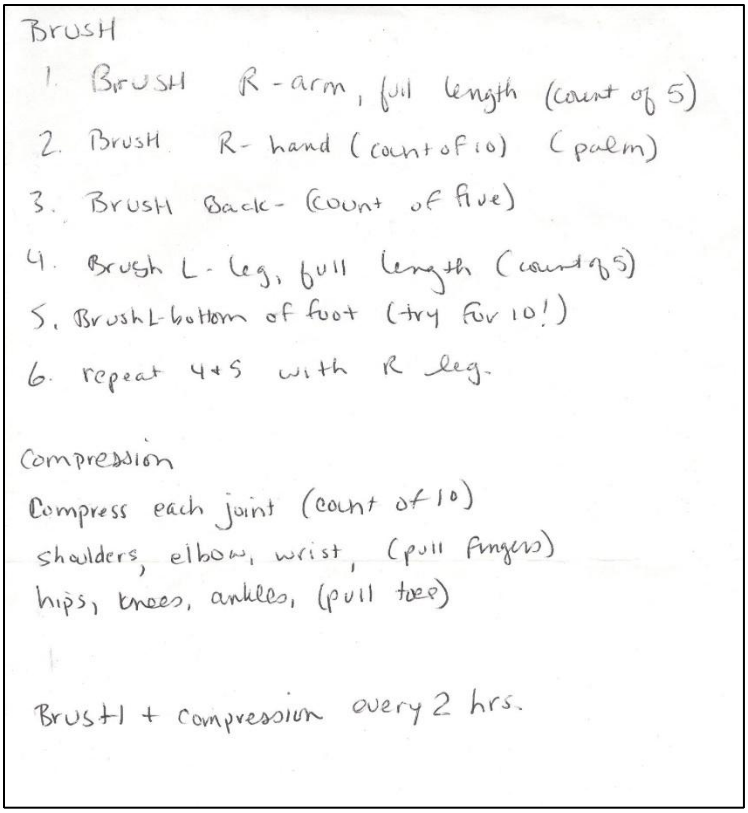
Harry’s sensory diet is below: (from my slides 2007)

Brushing (skin, not hair)
Joint compression
Chin up bar
Swings, swings and more swings
Carrying/pushing laundry baskets
Wall push-ups

massages
Laying on him
Watching TV from his stomach on yoga ball
Trampoline inside and outside
Use of weighted balls
Yoga ball

The most interesting and strange parts of the sensory diet were brushing and joint compressions – done together. My hand-written instructions are below:

Figure 2: Hand-written Example of Sensory Diet Instructions



BrusH

1. BrusH R-arm, full length (count of 5)
2. BrusH R- hand (count of 10) (palm)
3. BrusH Back- (count of five)
4. Brush L- leg, full length (count of 5)
5. Brush L-bottom of foot (try for 10!)
6. repeat 4+5 with R leg.

Compression

Compress each joint (count of 10)
shoulders, elbow, wrist, (pull fingers)
hips, knees, ankles, (pull toes)

Brush + compression every 2 hrs.

This was done at least 3 times a day at home. They also did it once a day in school. It mattered. One of the most obvious measures was the use of brushing and compression after speech therapy. Harry was taking private speech therapy. They were long sessions and very intense because they were one-on-one. The therapist kept Harry engaged and they often did mouth or tongue exercises. When the session was over, so was our day. Harry could not engage in anything – he was almost at a stage of constant meltdown. I thought he needed to relax – so I would put on his favorite train video. It did not help. I also tried something active – so we would go outside and peddle his bike. It did not help. His OT therapist recommended the brushing and compressions. So, right after the next speech session, we went into the hall way and I brushed him and did compressions. It was like magic. I got Harry back. It became a go-to home strategy.

Speech and Language

Soon after Harry's diagnosis, Harry started Speech and Language therapy. We were seeing a very well respected private therapist. Speech services for articulation were $50 a week. Add a social skills group once a week for another $50. We paid upfront. I don't remember if and how insurance worked. I just remember the expense.

The therapist actually started working with Harry in her home. Her home was quite fancy, as a two-story brick with a large open foyer and grand staircase. We would take off our shoes in the foyer. There were multiple display cases housing expensive and breakable objects. I remember trying to hurry Harry up the stairs to the therapy room. However, Harry was afraid of heights, and his anxiety would make it difficult for me to get him upstairs. If he started to flail, I worried he could do so much damage that I would carry him up the stairs.

The social skills group was interesting. The therapist would put a monitor in the room with the boys so we could hear them. Three other mothers and I sat around this baby monitor, listening to our kids. We didn't speak. We didn't laugh. We never wanted to offend each other. At the end of the session, we would scoop up our kids and leave. I think one time we all went to a nearby park after the kids' session. I just know speech therapy was incredibly hard, and it was some time before I started with the compression and brushing at the end of the session.

We worked with the private therapist until we moved to Williamston. At that time we connected with the school speech and language therapist. I remember when I met her at an IEP ("Individualized Education Plan") meeting. She was refreshing. I wondered how long she had been at the school. I was not surprised she was coming from consulting and this was her first year at the school. She became our guide. She worked with Harry in so many ways but my favorite was the use of foreign films – used silently for the students to understand emotions and relationships and roles. I do believe it translated to real life. She was a favorite of Harry's. When budget cuts forced staff changes, I was not surprised that the contract for this outsider was one that was not renewed. For her, the librarian, and the science teacher, Harry wrote and delivered a speech to the school board meeting about their importance to the school and to him. He wrote it himself and I took him to the school board meeting. I was more nervous than he was. He signed in and we waited. The meeting started and public comments were welcome. We were the first ones on the list. Harry stood up from the folding chair and walked to the center of a U-shaped table arrangement. He read his speech. The room erupted with applause, with many people standing. Harry looked surprised. He walked back to join me. He asked me if it was ok. "It was wonderful, Harry" I said. "Do you think it will make a difference?" he asked me. I told him that it already had.

Like many kids on the spectrum, he also did not always understand the dual meaning of words or slang. I remember my brother, football in hand, saying "Harry, go deep". Harry stood his spot and slowly bent his knees moving down into the grass."Deep" to Harry reflected a submarine dive. He had to work on understanding language in their context so improving social skills was important. The Autism Instruction (AI) consultant at Harry's school ran an afterschool social skills group that met once a week. It was fabulous. Both Harry and Isabel attended. There were boys and girls in various grades (2-4th) with a wide range of issues, plus some siblings. Using the book “The Hidden Curriculum”, they would work through a topic or address an issue of particular concern. I think it was very helpful for Harry to know he was not alone at school. Two friends from the group are now also part of our social farm. Budget cuts ended the program as the AI consultant had to move jobs and the new consultant was not interested in continuing the group. She stated that there was not any evidence based research that support peer-to-peer social skills groups. In Harry’s middle school, the offered program now is a mentor relationship program known as a “Peer-to-Peer Support Program that involves students with social needs and students nominated by their teachers as positive role models” (one student with ASD paired with one without ASD). The student with ASD is the receiver –the “target” for assistance. The student without ASD is the mentor – the provider of assistance. Harry would not have the opportunity to co-mentor. There is training offered for the “nominated” students, and not the “target” students: (email from AI consultant)

> 1. Psychologist: Provides students with an overview of disabilities and how the disabilities impact socialization
>
> 2. Social worker: Provides students with an overview of how behavior is impacted by disabilities
>
> 3. Speech/language therapist: Provides students with an overview of speech & language skills (pragmatics, fluency, reciprocal conversations) and how disabilities may impact these areas
>
> 4. All adults involved will provide training to students regarding strategies/tools/ideas to assist students with social needs
>
> 5. Question and answer time
>
> 6. Program expectations (on-going)
>
> Nominated students will receive training one time per month. The two peer groups will participate in a social luncheon/recess activity one time per month.

We questioned the program in an email to the middle school AI consultant:

> The component that I'm not hearing in this program is a consideration of the participation of the 'students with social needs', beyond the presumed benefit for them of participating. There is no mention of review with those students for their opinion and perception of the program or of their peer counselor, nor of determining their interest in participating in the first place. To me, both absences are critical flaws.
>
> I welcome education for anyone about how to better interact and consider people on the spectrum, including the students nominated to serve as positive role models. An essential component of that instruction must be learning to recognize that every student has opinions and perspectives that are credible and have value and should be considered. In short, ask students questions and listen to their answers. I think that is lacking in this program, with respect to the students on the spectrum. It's a disservice to students on both sides of the program to structure this as something performed by the 'nominated students', and performed on the 'students with social needs'. We can't be part of that. If there is program where all students are peers and the exchanges happen in both directions, we would be eager to participate. Please correct me where I'm mistaken. I appreciate the value of social skills education, and will continue to look for a model that gives kids on the spectrum appropriate consideration.

Her reply:

> In regards to your concerns regarding the Peer-to-Peer Support Program, you are welcome to attend the START Peer-to-Peer Support Training to learn more about the program's components. The training is free to all educators and parents. I have checked Ingham, Eaton and Clinton county professional development web sites and no Peer-to-Peer trainings are being offered between now and June. One or two sessions will be offered in the Fall (201)2 if you are interested in learning more.

So, we opted out of that program and if we needed to learn more – we can go to training next year. I believe that any program must be mutual in voice and power, especially if the free and informed choice is difficult to ascertain. Any program should promote positive socialization and recognition of differences in a mutually respectful way. This is true for any child. For inclusion, this foundation is necessary. The Peer-to Peer school sanctioned program is structured to emphasize the challenges of one group of students and places the students in a subordinate role as those who need help but have nothing to offer. This further isolates children with ASD by emphasizing their differences and continues to perpetuate the falsehood that this group does not have a voice worth listening to and learning from.

Music Therapy

We started Music Therapy at MSU. It was a process: first, to get him out of the car; then to get him into the building; and then to get him into the classroom. Harry was reluctant. He was always reluctant to try something new or transition to a new activity. I had learned to provide information to Harry upfront and in a visual picture schedule. We would talk about activities in detail. However, the new building and new activity meant that it would take time (and a couple of sessions) until I got Harry into the classroom. However, once we were there, he LOVED IT. The therapist was amazing. She engaged Harry in the instruments. He would play the drums and she the piano and they would sing, often about pirates. They played loud and Harry seemed to play with his soul. I wish now that I video-taped it but in the moment, I would have hated to constrain any of his freedom. Harry went from not wanting to go into the school to looking forward to music class to asking “when is music?” It was a strong connection for him.

Perhaps that is why this is so very sad – at a session, a man (cello instructor) came in the door yelling at Harry to stop, and saying that Harry was interrupting his cello session, and he could not teach under these circumstances. The look on Harry’s face was one of utter astonishment – a wide-eyed deer look. I too was taken aback at someone yelling at my son during a therapy session. The therapist was flushed as well. After an exchange between the therapist and the man (and the man left), the therapist tried to re-engage Harry. I tried to be positive, but at the end of our session, I walked my kids to the car and then called Joel. I called from outside the car, away from the kids, because now I was crying and mad as hell. I told him what happened. I did not know it at the time, but Joel immediately went to the music school and confronted the cello teacher during a lesson. Below is Joel's letter to the music therapy school, written the next day. The letter below was how it ended (written by Harry's father in March 2007)

> Dear Ms. K,
>
> My son, Harry Szymecko, is enrolled in a class at the CMS, and we need to let you know about an incident which occurred during his class yesterday, March 15.
>
> Harry was with his music teacher (therapist) for a regular session, Thursdays at 6:30. This music room contains a drum set, which Harry plays every week, and it is the instrument he usually selects. During a song, while Harry was drumming and singing, a cello instructor from the next classroom interrupted my son's session and, in the presence of the child, told the therapist that they should stop the noise because it was interfering with his lesson.
>
> The classroom has a Music Therapy sign taped to the door. The room number placard includes the therapist's name and "Music Therapy" as the subject for the room. When the music therapist told him that it was a music therapy room, he left. The therapist continued the session and Harry finished the class, although his mother said that his reaction and withdrawal were visible.
>
> In a later explanation to me, the cello instructor explained that I needed to understand that "from where he was sitting ... the sounds coming from the room seemed like noise ...", but when he realized what was "going on" in the class, he "understood" and "had no problem" with the sounds. While responding to my strong assertion that the interruption and his actions in front of the student were inappropriate, he expressed empathy for what my family was "going through" and repeated that he now "understood what was going on" in the class.
>
> Harry describes his music class as one of his most favorite things, when very few activities ever get that kind of expression from him. He has moved from fighting not to enter the school on his first visit and being too concerned to even touch the drums, to looking forward to his class and playing the drums with abandon and curiosity. The music therapist has been wonderful with Harry, and his positive response to her approach has been apparent from the first class. His experiences at the School have been a pleasure for him, and a place for him to expand his confidence and explore with play. His experience has now been expanded to

> include this reproach from a person who is a stranger to him, and the characterization of what he enjoys as "noise".
>
> The cello instructor's response to me is as difficult to understand as the interruption of the session. What was "going on" in the classroom was a teacher and a student exploring music and enjoying learning, just like in any other classroom at the School. Until tonight, what our family was "going through", was experiencing the pride and pleasure of seeing our son explore music and spend time at an activity which he truly enjoys.
>
> As parents electing to participate with our child in the music therapy program at the CMS, we assume that the School, as a whole, is receptive to all students and supportive of their efforts. We would also assume that addressing issues which are not our own would not subject us to comments which are patronizing and condescending.
>
> If teachers have any requirements about ambient sounds during their lessons, we would expect that issue to be resolved with the School, and not by attempting to constrain a student, which was not their own, during a private lesson, which was not their own. If that resolution is somehow not possible, we would expect that teacher to attempt to resolve it privately and appropriately, and not in the manner we witnessed. Please find this instructor a room with the privacy and sound level he requires. And please remind him that the School is open to students and instruments which are not subject to his approval.
>
> We are hopeful that Harry will be able to continue to experience making music in a supportive and respectful environment. While we would rather not have the need to deal with issues of acceptance and respect, we will make the effort to help resolve them.
>
> Please feel free contact us by email or phone. Thank you for your help.
>
> Regards,
> Joel Wallace,
> Harry's father

We wanted to continue, and tried, but never signed up for another semester and I have not been an advocate of the Community Music School because of how they responded. THEY DIDN’T ACT. On April 16 I received an advertisement from the Community Music School for their music therapy camp. Below is what I sent to the school:

> C,
>
> Thank you for the update to the list serve at MSU. My son, Harry really enjoys music therapy at MSU. I have not heard of the outcome since his "barge-in" incident at class a few weeks ago. We wrote a letter to the school and I can forward that to you. I would feel more comfortable endorsing the program when I understood the policies that protect the children in the therapy program. Please feel free to call me or respond via email.
>
> Thank you. Lisa Szymecko (letter attached)

Her response:

> Hi Lisa,
>
> First of all, I deeply apologize for that incident!! I will take the blame because I do lots of PR and talking about music therapy and what we do, but never to my co-workers at CMS!! I sent out an email explaining music therapy, the confidentiality issues and emphasis on "celebrate abilities' to all of the CMS faculty after the incident. I'm sorry that I didn't do that before, but hopefully this will help prevent any future incidents. The associate director of CMS, also talked to the individual who walked right into the session and made the comments.
>
> Have you ever read Judy Winter's article "Look into my eyes"? I will attach it to this email, just in case you haven't read it yet. (It will definitely "hit home" with you after this incident…) I am posting this at CMS and MSU College of Music for people to read. I think TOO many people are not yet able to see all people as people first!!
>
> I know that our associate director, was planning on contacting you and Joel regarding what we have done to try to prevent future incidents similar to yours. I will forward this to her. I really am sorry that Harry's session was interrupted and that our CMS faculty became patronizing while trying to apologize for his behavior. Please let me know if I can do more to help with this situation.
>
> C

We never heard from the associate director. No one from the Music School apologized to the individual that they harmed – Harry. Instead they want me to understand that people may not view him as a person – and it is even written in the poem. They did not create a safe and nurturing environmental for Harry. And, they, themselves, did not feel Harry was person enough for an apology. Fuck the poem. We never went back. Life is too short to put up with therapy that is not participant-centered.

Dr. S.

I took Harry to see Dr S. in Ann Arbor. Harry's pediatrician gave us his brochure when I confronted her with Harry's diagnosis. Dr. S. does not take insurance. This was another obstacle – the cost of upfront charges with the hope of reimbursement.

Dr S. was incredible. He connected with Harry. He would tape record sessions so that I could use his words to be a better advocate with Harry. He introduced us to 'floor time', a behavior-based therapy using play to teach and extend interaction. Dr. S.'s observation was about the level of imaginary play Harry was engaged in, and that my role was to help him move up the development ladder. Harry was a setter-upper. He liked to place his dinosaurs very carefully throughout his room, our room, the house. His dinosaurs did not talk. They were not families. They did not have names. They did not speak with a French accent. I could play dinosaurs with Harry if I sat next to him and didn't bother him. We were parallel playing – he did not let me in. Dr S. helped me first see that I was being a mom – I knew what would upset Harry and so I did not do those things. I did that almost subconsciously. I played with Harry in a way that Harry let me play with him. So, I was on the floor, lining up my own dinosaurs and I could get a trade from Harry now and then.

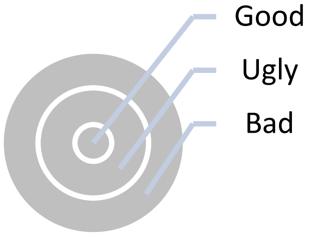
Dr. S. explained that I had to play with Harry in a way that helped him learn to engage with others, yet not have a meltdown. Oh, it was so hard, at first. I would often get frustrated because I felt I could not do things right. Our play ended in two sets of tears: his and mine. I remember having to give us both some time and space and we worked to have dinosaurs talk. Harry was never thrilled at the transition from playing alone to playing with me. It often took rewards to try something different. This is still a struggle.

Sometimes I would go to Dr. S.'s office alone to help me with Harry's behavior and what I should do. My notes say that:

> Joel is mostly angry as he tries to get Harry to do something routine or if there is a different expectation. It is really a strong arm tactic.
>
> Harry is excited, distracted. He runs away from me and hides. At the MSU organic farm pick up, he hid in an outbuilding. It was dusk and he would not respond to my calls. I could not find him and was only feet away from him and did not see him (and he said nothing!)
>
> Harry is also lashing out. He is hitting me or grabbing izzy's checks. It is rare for him to touch his dad but he will say things to him like "worst dad ever"

Dr. S. explained bad behavior breaks rules, ugly behavior we ignore, and good behavior we reward – even if it is moody.

Figure 3: Behavior diagram



He had us document Harry's behavior (how often/how long) and if we could anticipate what was triggering his behavior. We had to help Harry decompress when he gets home. He should be rewarded for cooperating. If there is a conflict, we should engage – present sides-turn into a process – we could fight-what do we do-talk about it. Give a prize from the dollar store.

Harry's response to conflict was to stomp upstairs and go under his covers and cry. I was to keep him engaged so he could not withdraw. We could go on the trampoline or hip hop or an activity of his choice. If I had to go to a room or bathroom to hold him, I could. It was important that Harry work through his anxiety.

So, he is having a meltdown – mad, angry and crying. He is lashing out. I keep trying to engage and do not let him retreat. I'd say he had to pick an activity. He wants nothing to do with me or the activity. I hold firm. We go to the trampoline. He will not jump. I say he had to 10 times. He is so mad at me. Finally he jumps. Once. This goes on for minutes. I am calmly talking to him saying "this is what we have to do when you are this angry. I know this is not easy. I want to help you." Finally, he jumps again. And again. It is working. The talking acknowledges his anger and the trampoline helps him cope.

I was having trouble with Harry in the car. Harry was having meltdowns, and at one point was throwing Matchbox cars. Dr. S. had me inform Harry about the consequences of that behavior, and then if it happened again, to follow through with the consequences. This means that we pull over the car and wait 15 minutes. We made it a social story so that Harry could see the natural consequences of his actions. Dr. S. emphasized that I should always be loving. Harry was learning.

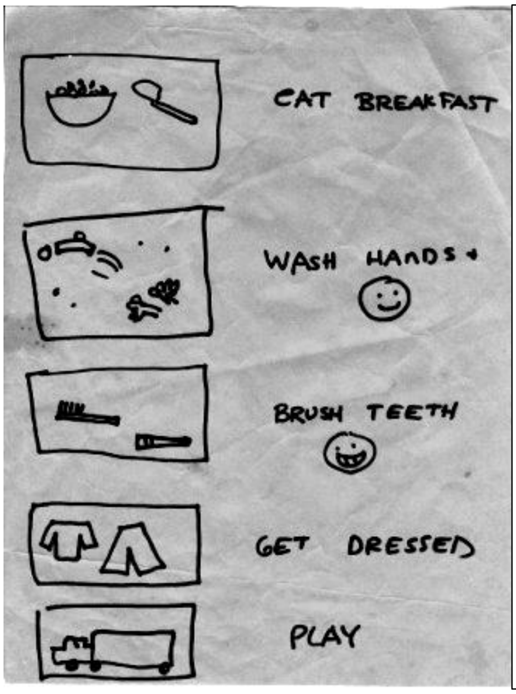
It only took one time for this to work. Joel was in the car with me. We pulled over and both got out of the car and waited 15 minutes for the screaming to stop. It did. We (pretend happy) went on our way. Stunned.

I went to Dr. S. for years, often alone or with Harry. It was not until Fall of 2011 that Joel did go to Dr. S. without me. I had made the appointment.

Home strategies

We brought the collective knowledge of individual therapies home and integrated it with Harry's day to day life. Brushing and joint compressions were daily activities. We slowly phased them out to twice a day in first grade to zero today. Visual schedules were used every day. We use a big picture (day or week) and detailed visuals schedule or social story for short activities. The schedule below hung on the refrigerator for years. Because the schedule is a bit crinkled from use, I included the typed words for clarity.

Figure 4: Harry's Handwritten and Actual Visual Schedule



Eat Breakfast

Wash Hands

Brush Teeth

Get Dressed

Play

For days that are not structured such as weekends or time off of school, there is anxiety.

> **Below is a note from Harry on a Saturday**
>
> "Dear Guys,
> I have no idea what to do today. If you think me stomping up the stairs meant I was mad, guess again. I just ____ this last part is in a secret language. Good luck."

In the summer of 2007, I had two nieces (sisters) graduating from college on the same day but in two different states. My brother rented a bus to drive the family around for the entire day. For Harry, I had him make a picture of each of the events and the bus ride in between. Then, I used an iron on application to transfer his visual schedule to his T-shirt. We made one for his sister too. This was the best way to help him through a day that required a lot of personal control.

Detailed outlines that show or explain an activity (social story) were also extensively used. For example, in kindergarten, they have carpet time every day. Children sit on the carpet with their legs crossed and engage in group activities and discussion with the teacher. Most kids hear the teacher's instructions and fill in gaps by observing others. Harry had a very difficult time with verbal instructions and it was nearly impossible for him to understand more than one step direction, verbally, if at all. So, his teacher and I put together what it means (and doesn't mean) when there is carpet time. Once Harry understood the behavior that was required, he worked to comply (with re-direction). The teacher would be able to place a hand on his shoulder or sit/stand nearby him or use a hand signal only he knew so that he was not constantly being called out. That still works. Successful teachers adopt it, often sharing that from one teacher to another as Harry moved through the grades. Harry's best year(s) were the ones where he looped in the classroom. He had the same teacher for two years in a row. That meant for us and for Harry, that she knew him and in that second year, Harry did not lose the first 2 months of school. Usually, it takes until about November for the teacher to call us in, to listen and learn strategies. We try to convey this in September but are brushed aside.

Another idea that we brought from therapy to home was a reward system. A reward system was a way to connect something tangible to a behavior/activity and in a positive way. If Harry was having trouble mastering an activity or overcoming a behavior– we would focus on that and reward success with Skittles (his favorite candy). Once his activity (or behavior change) was integrated into his life, the reward was not needed. This is always short term and focused. It allows Harry to see a positive consequence for his actions. Harry does not fail or feign failure in order to get a reward. Once he masters something, he moves on. We use this to help him be successful. It still works when he is learning new challenges.

We continued the sensory diet at home and at school using the brushing and joint compression. We installed a removable chin up bar so he could hang and have swings and once at the farm, we used swings, swings and more swings (there are 6 around the farm – all different). When he was very young we would have him carry and push laundry baskets filled with heavy items (canned goods and books) around the house. Wall push-ups (which were very helpful until about a year ago) were something we could go to. Massages worked if he could tolerate them, but he did tolerate (and enjoy) having us lying on him for pressure. We also use the yoga ball to sit and lie on, and trampolines inside and outside the house to jump on.

In spring of 2011, Harry was home sick so we watched the Temple Grandin movie. I was nervous but trusted the reviews so I did not prescreen it. We both loved it. Here is what I wrote after we watched it:

> So, I watched the Temple Grandin movie with Harry. I was hesitant but have always been transparent. We, both lying on the couch – each at their own end, covered in blankets. Harry has the Edmund Fitzgerald book he has been reading. When I asked him if he would like to watch the movie and he said yeah, he liked the other documentary (it was Marilyn Waring). I said I wasn't sure if this was actually a documentary (in case there was added drama) that I could explain – you know fact v. fiction.
>
> As we begun to watch the movie, Harry placed his book on the table, open-page down in order to save his spot but also, I think, as a quick go to, if needed. I told him that Temple Grandin was older than me and that people knew less than they do now. He said "of course but there are things they still don't know." I didn't have the were-with-all to ask what – I just agreed.
>
> When Temple Grandin began to make the squeeze machine – I asked Harry why she did that and he said "it was like a hug." She didn't explain that until later in the movie. He knew. I have used deep pressure to calm him.

> Then at the end, when Temple Grandin stood for her mom to hug her – I started to cry. Harry does that, too: he approaches me and stands close but does not squeeze – kind of like the actresses that “kiss the air”.
>
> At the end I was crying. Uncontrollable crying.. Harry asked “are you crying?’I wiped my eyes and I asked him what he learned from the movie and he said “cows like to walk in circles. It keeps them calm”
>
> I went to the bathroom and said that I would be right back and I wrote my notes and took my paper into the living room to write. Harry said “horses speak with their ears but also their tails”. He said he “could build the machine. I just imagine a guillotine without razors. I thought at first she was trying to commit suicide. Then I would rate it – like how much it worked for me. I don’t think anyone else would try it. A lot of people I know can’t see past certain things. They would say nice guillotine. It is like politics. They say “obama sucks” and that’s it. That’s politics. Sometimes dad does that. Then I told him about it and he said “really” and he will talk politics and then at the end say “and that sucks.”
>
> Harry went and got this book “New Understanding of Autism”. Harry says “I never thought in pictures. [pause] Why does the squeeze machine work and why doesn’t a hug? They are so similar and so different..,” And then he says they are similar in their squeezing action that puts pressure on your body. But the touch is different.
>
> I remember thinking it may be who is the controller of the touch / squeeze. And that the machine allows just the right input. I recommend the movie to Joel.

Harry had distinct interests. In preschool and kindergarten he did like trains but he was actually more into ships, especially the Edmund Fitzgerald. Because that ship was an iron ore freighter, his interest followed the iron ore to the steel making process, and then to the history behind all of it. He loved to read about and became quite knowledgeable about ships, ship wrecks and steel making. We encouraged Harry to follow his interests and supported him. In the summer of 2008 we took him (and two cousins) up to Whitefish Point in the Upper Peninsula of Michigan to the Shipwreck Museum. It was very sobering and sad to see all the artifacts from ships lost on the Great Lakes. Harry’s strong interest was not just in the facts, but with the history, and the people and their stories. For someone who, at the time, read many fact-based books, he read and remembered the stories of people.

He also was very interested in Henry Ford's story. We went on the Rouge Tour at the Henry Ford museum. It was Henry Ford's struggles as well as his passion and motivation that really engaged Harry. It may have been the steel making process that brought him there but it again was his story that has kept Harry engaged. Facts in historical context and people and their stories continue to be his passion, if there happens to be a ship or a Ford involved or a B-17, even better.

Oh, I don't want to write this part but I feel I have to. As I sit next to my 87 year old mother, I have to tell the story of Harry and my dad.

My dad was 79 when Harry was born. He and my mom practically moved in with us at our rental house on the lake to help care for him. I don't know how it happened, but there developed a very strong connection between my dad and Harry. I did not see it coming. Harry, well, was Harry – uncoordinated, prone to tantrums, and liked to play alone. Somehow my dad knew him well. They connected. Those two could sit and play the longest game of checkers I have ever seen. I mean hours. Harry also loved my dad's stories. He was in WWII as a B-17 gunner. That combination of personal history and a plane was a great hit for Harry, even at a very young age. Harry as an attentive listener that was authentically interested was a hit for my dad. When my dad turned 86, he flew in a B-17 (with my brothers and I) for his birthday present. It was amazing. Harry drew pictures of the plane and my dad hung it up in his kitchen, over the kitchen table. Then, Harry drew new pictures of the plane as he grew older. The new drawings were added to the place of honor. He made one was last year, 3 years after my dad passed away. My mom won't take them down.

But through this bond, my dad gave Harry his brown army dress hat. In first grade, Harry brought the hat to school for show-and-tell. He was very proud. In 2007, Harry wore it to a Memorial Day parade in Dansville. In the hat, he was asked to help carry the opening banner of the parade. It was so touching. Harry also wore the hat to my dad's funeral. It was his idea, not mine. In fact, when Harry asked, I yelled "NO!". But I realized it was only a gesture of love and honor so I allowed it. To see him in that hat, standing at the casket, was too much to watch. Now, it is too much to remember. Today, the hat, a picture Harry drew of my dad (Papa), a goldfinch statue, and an American flag are all placed in a glass case. Harry put it all together as a shrine to my dad, along with his funeral card. It is hard to believe it was 4 years ago.

A home strategy was also to have Harry participate in school activities. This required oversight – so full dedication of a parent. I elected Joel. Joel became Harry's coach for every sport he ever tried and his den leader for cub scouts. One time along this path Joel stepped aside and was not happy with the results – you have to lead for there to be change, you can't sit on the sidelines and complain. The biggest motivation to coach was to create an inclusive environment – so that regardless of ability, everyone participated. This was not always welcome by other parents who would like to win a game or two. Joel had to work with boys who would also complain about their teammates. It was also hard for parents of those that did not play well, to keep silent. They felt bad that their son was not performing like the others. I would reassure them that it was ok. Joel would say that the goal was to have fun. Joel says "every boy is welcome at every ability and the only obligation was that they tried and that they respected other players." Joel believes the outcome was positive. When practicing with other teams, Joel says his players interact better with each other and to players generally. They were less whiney and maybe more encouraging to their teammates. He also says that he had high retention and that boys that did not make it other places, felt welcome. Parental feedback was very positive. My role seemed to be a parental point of view, an advocate for Harry, and sometimes his defender in the stands.

School

I never imagined separate but equal schooling for Harry. I was unaware of a whole subculture of parallel public schooling for those who, for whatever reasons, were not integrated into the classrooms. Inclusive education means that all students in a school, regardless of their strengths or weaknesses in any area, become part of the school community. The Disabilities Education Act (IDEA) and its 1997 amendments make it clear that schools have a duty to educate children with disabilities in general education classrooms. *Inclusion* is a commitment to educate each child, to the maximum extent appropriate, in the school and classroom he or she would otherwise attend.(Huston, 2007). Inclusion is part of a much larger picture then just placement in the regular class within school. It is being included in life and participating using one's abilities in day to day activities as a member of the community. (Kidstogether, Inc. 2008) There is has been much debate on inclusion, the requirements, the cost, and the outcomes. (Huston, 2007) Students in special education and regular education have shown several positive changes from inclusion including reduced fear of differences, social growth, and warm and caring friendships. (Huston, 2007).

Harry was in an inclusive preschool. His teacher helped us with early diagnosis and worked with us throughout the process. She was my teacher as well. She helped me understand child development and we talked about strategies that worked in school that I would try at home and vise-versa. Harry’s preschool set the bar high in terms of parent-teacher partnership. His teacher also helped me with the transition to kindergarten. After Harry had moved on, SCDC asked me to speak to families about the transition to kindergarten, especially for those with special needs. But that was well after the kindergarten roundup incident.

Joel and I were at the kindergarten roundup for Harry. We had Harry's formal diagnosis and had started occupational therapy and speech therapy, but we were still in transition; I just didn't realize how much. Kindergarten roundup was held in the elementary school gym. There were a variety of tables, each representing an activity that a parent had to complete: a nurse table to submit health information; a bus table to sign-up for bus service; and others. Joel and I split up and I choose to go to the bus table. Harry loved buses. He wanted to ride a bus. I wanted to help him. As I waited in line, I could hear the other parents chatting about their son or daughter. I just kept worrying about Harry. So by the time it was my turn at the table, I was already close to tears. When I said I would like my son to ride the bus, I started to cry. The lady at the table asked if everything was ok. I said that my son was autistic and wanted to ride the bus, and I wanted to help him but I didn't know if he would be ok on the bus. Then I started to cry very hard and could not stop. The lady walked me to a room off of the gym and gave me Kleenex and I sat down in these really little chairs. I was trying so hard to stop crying but I couldn't. Joel joined me in the room. He saw me crying at the bus table – and could not imagine what was going on.

The lady (who later turned out to be his bus driver) reassured me that Harry would be perfectly safe on the bus and that she would make sure he had a very special seat, right behind the driver (her). I thanked her and apologized and a small group of people came into the room – the principle, a teacher and others. They asked me about Harry and I told them that he was diagnosed as autistic and they explained the IEP (individual education plan) process and how we would get together to make sure Harry's needs were met in the classroom. I gave them my contact information, thanked them profusely and Joel and I left. We never made it back into the gym. I felt better that we had a plan. I had stopped crying. Joel was quiet.

Harry and I lucked out in kindergarten. We had Mrs. Woods. She was magical. She let me into her classroom where I participated every Friday. I learned so much from her about how classrooms work. I would get to be in charge of a station – usually the art station. I think this was because it was the messiest. I would stand at my station while the children were sitting on the carpet. Mrs. Wood would ask them their preference – like “who would like to do the finger painting self portrait with Ms. Szymecko”. Students would raise their hands. Harry never picked my table. He would be looking down at his shoes, playing with the Velcro on them. His para-pro would help him navigate the stations. I was always happy to have him at my station. He would look up to me and I would say “Hi, Harry” and he would look down at the paper and say “hi mom”. Most of the students referred to me as “Harry’s mom”. At the end of the school year, Mrs. Woods gave me an oven mitt where all the students signed their name – a thank you for giving the class “a hand”.

We had Harry’s first IEP in the fall of his kindergarten year. It was supposed to be in September, then October and finally November. I called our school contact many times. Harry’s services were temporary until his formal IEP. Harry had services: OT and speech and language. Harry also had a para-pro (a classroom helper). The classroom helper would give Ms Woods a hand with other children, but was there to help and support Harry. She helped with re-direction; translating verbal instructions into tasks; and she helped identify when Harry needed sensory breaks and helped him maneuver socialization in the classroom. I thought the school was trying to delay – so that the services would not become permanent (they could have demonstrated that there was not a need). But, my being there on Fridays also helped schedule the IEP.

Being in the classroom every Friday also meant that people knew where to find me. It was not uncommon to have an impromptu meeting with either Harry’s speech teacher, or his OT, or to discuss Harry’s progress with his teacher and para-pro. It was through this informal contact that I found out why Harry was inconsolable on Tuesday nights. I had spoken with Mrs. Wood but could not figure it out. Then, just talking to one of the therapists in the hall one Friday, I realized Harry was receiving all his therapy on Tuesdays and feeling overloaded. The conversations were something like “oh, Harry goes to OT biweekly? And one of those days was Tuesday?” and “Oh, Harry does speech Tuesday mornings?” The services were just not coordinated. Although everyone was in the building every day – it was through our discussions that we stopped the overload for Harry on Tuesdays.

Being in the classroom on Fridays also gave me insight into the struggles of many children – which included fetal alcohol syndrome and unstable home lives. Harry had issues, but so many others did too, and the classroom brought this eclectic mix together to learn. Inclusion was good.

This was also the first year Harry tried team activities like flag football, soccer, and t-ball. Joel was the coach. That was the agreement between us. If Harry participated – so did Joel. I think that is where Joel started to have a stronger voice for Harry’s inclusion. Joel always made sure that there was good sportsmanship and that everyone played. Oh, and that there were snacks. To date, Joel has coached Harry’s sports every year, multiple sports, and was Harry’s den leader for Cub Scouts.

Table 3: Extra-curricular activities, by school year

Year	Grade	Joel participation
Spring 2006	Kindergarten	Coach: Soccer, t-ball, flag football
Fall 2006 Spring 2007	First	Asst coach: soccer Asst coach: baseball
Fall 2007 Spring 2008	Second	Coach: soccer. Den leader cub scouts Coach: soccer, baseball. Den leader cub scouts
Fall 2008 Spring 2009	Third	Coach: soccer. Den leader cub scouts Coach: soccer, baseball. Den leader cub scouts
Fall 2009 Spring 2010	Fourth	Coach: soccer. Den leader cub scouts Coach: soccer, baseball. Den leader cub scouts
Fall 2010 Spring 2011	Fifth	Coach: soccer. Den leader cub scouts Coach: soccer, baseball. Den leader cub scouts
Fall 2011 Spring 2012	Sixth	Coach: soccer

$150 and a cake can go far

We moved to the farm, and into a new school district, right before Harry started first grade. We spoke with the staff from the school district, and with staff at the school, and met with the principal. Harry's teacher had not been selected yet. When the bus driver heard about a new family, she came to our house to meet Harry. At the time, it seemed a little crazy. Looking back, I realized what a vital role bus drivers play in the lives of our children.

First grade was turbulent for all of us. Harry's teacher was not receptive of me being in the classroom. She did not want a partnership between parents and the school, at least one defined by me. These are the statements she made to me (which I captured and used in a presentation that spring).

> "Boys will be boys" when another boy was rough-housing with Harry at recess.
>
> "He was wild all morning" referring to Harry in class. But when pushed she could not document any incident in particular or when it happened. I was trying to find out if there was a pattern.

> "It would be nice if all students had these opportunities" when at the IEP I requested for a quiet place for testing for Harry
>
> "And we didn't have to use rewards this time, isn't that great?" when a system of stars were used to document Harry's hourly activities.
>
> "He looks normal. Do we really want to call him out?" when I asked about setting aside some time to talk about autism in class
>
> "He clearly broke the school rules" when I asked why Harry was sent to the office after putting paint on a chair.
>
> "I don't understand why he was over there anyway. He doesn't like kickball." When Harry was pulled down by his coat by another child while she was in charge of watching the class on the playground.
>
> "We couldn't tell who all was involved" when I asked why the children accused of pulling Harry to the ground did not go the principal's office.
>
> "Sometimes I like to work alone too." When I questioned why Harry's desk was separate from everyone else's.
>
> "No one, really, but he is very well-liked" when I asked her about Harry's friends.
>
> "He doesn't look at it" when I asked why the visual schedule was not up in his class.

After 3 months of conflict with his teacher, I met with Dr S. and he dictated pages of solutions which I sent to school. Then I called a meeting with the school to amend the IEP with a copy of his recommendations and I brought a coffee cake. Every item that Dr S. recommended was implemented. The visit with Dr S. was $150. The coffee cake was zucchini chocolate. The change in his classroom – priceless.

Dr S.'s suggestions began withputting Harry's desk back with the class; inclusion was more than physical placement in the classroom. A visual schedule was placed back on the board. But one of the best solutions was a stars reward system. His teacher was required to monitor Harry once an hour and either leave a blank or a star on the paper. The star would mean good behavior, attending to task, and allows some re-direction. The result was that Harry was actually capable of doing his work and he did it. Up until that time, he only brought home blank worksheets. When I asked about them, the teacher said that he could not finish them but the truth was, he wasn't doing anything. With the star reward system, the teacher had to do more about helping Harry with free time. This unstructured time left him wandering around the class. She had to help him find books or activities. The behavior that she described as "wild" was never recorded under the star reward system. Once she had to document his behavior every hour, it seemed like it disappeared. He instead took his required sensory breaks. We also asked that he stop going to the principal's office and come up with a better plan. If Harry thought he was wrong, he would say he was sorry but that did not help with impulsive behavior. If there were issues, Harry was to go to the resource room.

With Dr S.'s help, we were successful with inclusion, except we still struggled with socialization. But Harry didn't have a problem with voice: it was April, autism awareness month. Harry's para-pro was very pregnant, and often in the bathroom. There was a substitute teacher in his classroom. The teacher, AI consultant, resource room teacher, and I had met twice discussing Harry and an autism discussion in class. I was for it. The teacher was not. Well, on this particular day, Harry had brought to school his book, "All Cats have Aspergers". He told the substitute teacher he was supposed to read it. Harry did read it, to the entire class. There was a short discussion about autism that the para-pro was present for. The reaction was calm. The kids liked the book. And Harry, despite the meetings and the concerns, outed himself to his first grade class.

Specials

Inclusion in school also meant inclusion in the school “specials”. These were the classes outside of the main classroom and they constituted music, gym, and art. The unstructured and more organic classes, especially gym, resulted in notes home such as “disruptive behavior”. Gym was loud, chaotic and the teacher used predominately verbal instructions. It required Harry to look around, observe behavior and follow. He would jump on the padded walls instead. It seemed like all the work within the classroom did not trickle into the specials. The environment was also more challenging for the para-pro. Even when Harry was on task, there were troubles in translation, for example, rollerblade day in gym. The instructions from the gym teacher were that once the helmets and safety gear was on, students could skate. Harry put on his elbow and knee pads, grabbed a helmet and put on his skates. But when he tried his helmet, he could not get it to fit his head. The helmets were on the other side of the gym. So, Harry began crawling across the gym, in his skates, to get a new helmet. This created quite a reaction. He was assisted to the sidelines where he took off his skates and got a new helmet. It was only then that someone helped him adjust it. All the helmets were adjustable. He tried to get his skates back on, but gym was over. It was after this incident that I just lost it. He came home very upset about gym. He blamed himself.

In previous sessions with Dr. S., he told me that Harry could quit gym. If it was overwhelming for him, he did not have to do it. At first I thought that gym was an opportunity for movement and social interaction but talking with Dr. S. I realized how very difficult it was for Harry and it was not his fault. However, I still kept him in gym. But now I thought that it was hurting his self esteem so I asked for a meeting at school.

The gym teacher had agreed to come to our monthly team meeting. It was probably second grade when these started. The AI consultant, teacher, speech teacher, OT, resource room teacher, and any others would meet right after school for a short time to try and catch issues before they became overwhelming. I remember the hesitancy of his second grade teacher, not wanting to make a big deal out of it, but cautiously raising her concern about Harry blurting out in the classroom. The others on the team knew Harry from the year before. They offered advice about structure and clear rules as well as key words like “Harry, I hear you have something to say. Can you raise your hand”. They also recommended having Harry close to the front of the classroom, having the teacher be able to place a hand on his shoulder as a reminder, or showing the teacher a hand signal that Harry understood (if she did not want to always verbally call him out). The teacher was thankful. I would offer what I saw at home and what worked for me. I would also offer to reinforce positive behavior at home. This built an open dialogue and a willingness to learn and share. Harry was present for the meetings as well, reading. But we engaged him too.

When the gym teacher came to his first meeting, he was very open. But, it was as if he did not even know about Harry. He talked with the teacher and the team. A plan was developed. Harry would go to gym a few minutes early and meet with the gym teacher. They would talk about the plan for the day. The gym teacher would show Harry a visual in the gym he could go to – a schedule. It worked. The next report card was “Harry continues to improve in gym and is a pleasure to have in class”. I cried. The gym teacher cared for Harry. They developed a great working relationship. Sure, Harry still would bounce off the walls on occasion. But the gym teacher knew how to re-engage. He knew Harry. Harry began to like gym.

The next issue was music. Harry loved music and would move with the music. However, this music teacher preferred the class to sit in chairs. Harry was sent to the office multiple times for disruptive behavior. Once, the teacher asked him if he was goofing off, he said “yes” although those around him said “no”. Harry does not lie. He was sent to the office. The music teacher acted surprise when we asked her to come to a meeting for Harry. But at our meeting she had a long list of things he did wrong. When I asked her what he did right, she remarked “I cannot keep track of over a hundred students”. It was agreed that Harry would sit in the back of the class, that he would be allowed to stand, he would be allowed to leave at any time, and if she thought he was disruptive, she would not be sent to the office, but to the resource room. Sometimes you just have to solutions that will work, not that they are the best. The music teacher was also a partner with us, but was not interested in learning about Harry but keeping her own class in line.

IEPs

In third grade, like each year, we participated in Harry’s fall IEP. Required by any public school student with special education, it is a legal document that in theory, parents, administrators, teachers, therapists all have input into. It documents the qualifications of your child for services and what each team member will do for the year and how it will be measured. The IEPs are done every year but qualifications for services are determined every 3 years. This was Harry’s year for review. When I agreed to Harry’s IEP date of September 30th, I asked if there would be anything special for this year, and unknowns that I should prepare for. I was assured that this would follow the last three years. So, the Friday before his IEP, I turned in my parent input form to the school and received another form to complete. At that time, the school psychologist began to ask me about labeling Harry autistic and that the school (not the ISD –

which is where the AI consultant is from) can make a more favorable determination, because (as she raised both hands to her eyes forming two circles), she said "we don't want people to view him through ASD goggles". Taken aback, I stammered that we had long gotten over labeling concerns. I don't remember how the meeting ended. I do remember being very upset and given that this was Friday night, I stewed about it all weekend, searching the internet and in general, freaking out, which for me is a combination of coherent points and escalating anger and food. Tuesday came. I met Joel at the IEP meeting. That morning I wrote the following and read it at the start of the IEP:

> I have two issues with the scheduled IEP for Tuesday, September 30, 2008. They are outlined below:
>
> 1. As a parent and team member, I was not given any time to access, view or analysis the findings from Harry Szymecko's assessments prior to the meeting today, Tuesday, September 30.
>
> 2. I don't believe parental input was used in the decision making process. On Friday, September 26, I returned 2 forms and at that time, was given a form to complete. Also at the meeting on Friday, the following comments were made in regards to Harry:
>
> a. "Labeling is doing him a disservice". When I commented that Joel and I have gotten over the label, I was told that "you don't want people to look at him with ASD goggles"
> b. "Nancy won't let him go"
> c. Everything should be done "in-house", there is no need for the ISD involvement
> d. He can receive services under a different diagnosis
>
> It is my understanding that these comments are actually the final conclusions and these were made prior to any input from the parents.
>
> Without the time to review the team findings and without opportunity for parental input, real parental input, I disagree with the IEP.
>
> Sincerely,
> Lisa Szymecko

The social worker was the first to speak. She was a wonderful and kind lady who in the past, had helped me with bullying issues at the school when no one else could hear me. When others in the room said “we have a no bullying policy” in response to playground acts of bullying, the social worker said “Lisa, we hear your concerns that your son is being bullied”. She reflected back to me my words and it gave everyone pause. She gave me a voice. This time was no exception. She clearly said “Lisa, I hear that you feel the IEP would not be adequate because of the lack of input by you and Joel. We can reschedule it to make sure your input is included. Would that be alright?” I nodded. I had written and read the letter because I knew that meranting in the room would just not cut it and I could not trust myself to be calm. Joel was surprised by the whole ordeal and very supportive, even if it was after the fact. Back in the car, I started to cry. We went out for coffee. I phoned Dr. S. for an appointment.

One of the big transitions for Harry was his attendance at his own IEP. Harry had been coming to his monthly meetings, but IEPs were different. They are very pointed. They ask what are the strengths and weaknesses. Each person on Harry’s team participates. It is hard as a parent to hear and read the reports. Sometimes the negatives block out the positives.

Harry and I talked about it a week before. I needed to give him time to think about it. A few days before the meeting we spoke about it. I explained the strengths and weaknesses part and had him think about his own answers. I agreed to bring Skittles. I always bring a snack for the team and this was what Harry wanted. I bought the largest bag of Skittles at the store. The morning of the meeting, we were all gathered in a conference room. I was nervous. Eight adults and one child.He talked about his strengths (drawing) and weaknesses (messy desk) and his comments were recorded on the computer and projected onto the screen. At some point he asked me if he could read. (which I said yes) and he read and ate Skittles for the rest of the meeting.

At the end I told him how proud I was. He said it was “alright”. We made a big fuss at home that night.

The next IEP, I brought Skittles and Harry came but was quiet. We had not prepared. On the ride home I started to cry. Harry asked what was wrong and I yelled at him. “That was your chance to talk and all you said was “fine”. This is your life and your voice.” Harry said he was sorry. He told Joel that I was mad and he correctly said why. Fortunately we had another team meeting not too long afterwards. When I told Harry about it, he looked at me with wide eyes. He knew what that meant. And he didn’t disappoint. Given time, preparation, and Skittles, Harry was developing his voice.

At sixth grade it was all new people and I wanted Harry to be present. But when they said he could go back to his class I said OK. In the moment I agreed that he should not miss his classes, but I shouldn’t have. Harry was unable to contribute, not because he was quiet, but because he wasn’t present. And that was my fault. Fortunately, there was another meeting with all of his teachers. This was similar to my old monthly meetings. Harry was present – the entire time and participated. They would ask him what they could do to help. Harry was pretty clear – his boots did not fit into his locker. The math teacher offered his classroom space for Harry’s boots.

When I asked Harry for advice about the IEP he said that in the beginning, he would have liked to have a friend there. When I asked him would it be difficult to have his information out with his friend in the room, Harry said “no”, that the IEP did not cover deep dark secrets. And then he would have a friend to turn to. He also said that he didn’t need anyone now (in 6th grade). He was ok going in without a friend.

Autism and a sibling

I remember talking to Dr. S. about Harry growing up with a sibling and he said “you have to protect him”. I told him, “I know that Harry can be challenging.” He was more apt to take out his frustrations with me than his father. But Dr. S. corrected me; telling me that I have to protect *Harry*, not the sibling. I was very confused but he explained that Harry will need his space, a safe place to go, a place that his toys are not under constant attack causing him great anxiety. He needed a place of his own. I began to understand Harry’s needs. There was a grey line between fostering togetherness and Harry having his own time and space. One of the most positive outcomes was the increased involvement of his father. For some time after Harry began therapy, Joel had not taken Harry to therapy by himself – I was a control freak and Joel was withdrawing. As Isabel grew and needed space and attention, Joel started taking Harry to OT. It was a great way to learn and really increased their time together. It really was the forerunner for all the time and coaching that was to come.

I did a presentation in 2008 about Harry and Isabel. I wrote that as Isabel spends so much time at therapies for Harry, I was trying to find something just for her. She started dance lessons. I was trying to promote her own self esteem as she tries and learns new things because Harry was very critical of her. Isabel was engaging in more pretend play and at this age had started to say “that is just Harry”. At this time Harry was seeing her do things, easily. He was trying to navigate the day with her but needed space. I had to work with Harry to prevent his constant correcting and policing of her actions. I was not sure if he was competing or just sudden awareness on his part. Harry would act without regard to her safety. I was trying to have Harry look out for her. I had to make sure he allowed her to enter the bus first in the morning. He was unaware if she was on the bus on the way home from school. Home strategies that I used to help both of them included the visuals (schedules) and structure but I worked to set clear rules/norms so that they both knew the natural consequences. This was helpful for Harry to hear the consequences for Isabel. We also started brainstorming and setting priorities, especially on the weekend as a way to structure the weekend days. We would use a chalk board and dry erase board and identify things we would like to do and have to do and then we would pick and prioritize them. We avoided generalities like “free time” because that was also a cause for anxiety.

In terms of behavior, I used the phrase often that “everyone is different”. To help with perspective, we did a lot of role playing. This also helped each of them understand intentionality. A February 2009 interview revealed their thoughts about each other: The following questions were asked of Harry and Isabel. They were separated and told that it was ok to speak freely. I was not asking them to tell on each other and no one is going to get in trouble.

Isabel answered:

1. What do you like to do?
   Ballet and skating

2. What do you like to do in your spare time?
   What is spare time? (I explain)
   Draw, play games with mom and dad. I like to take pictures. I don’t know why but I have pictures in my pink camera

3. Describe your family
   My mom and her name is Lisa. My dad and his name is Joel. My brother Henry but we call him Harry. He has two names. My name is Izzy or Isabel.

4. What do you like to do with your brother?

- I watch him play Wii
- I make characters in his Wii
- There are games but I never do it with him, isn’t that strange?
- Play stuffed animals with him. We get out the stuffed animals and build stuff and real stuff happens. Harry’s animals don’t really talk
- Oh, I like to watch movies with him

- When I don't feel good he really helps me. He gives me stuff I wanted and helps me pick a movie.

Harry answered:

1. What do you like to do? What do you like to do in your spare time?

- I like to read, ride my bike, eat, baseball, play with my remote control cars and stuff
- Read and play video games
- Play with Izzy….

2. What do you like to do with your sister?

(Harry got very quiet and fidgety)
Sometimes she wants to play family and sometimes I play with her
(How?)
Usually I have to be the dad or brother and Izzy is the mom or sister.
(What do you do?)
Pretend we live in a house and she plays with her babies and we have a bunch of animals. I play the Wii.

3. Describe your family

What do you mean?
I don't get it
I don't know
I am bored
I don't know why you have to ask me questions
I don't know anything about my family

Even at three years difference, Isabel knows her brother. Harry raises two issues with siblings of children with autism: the extent to which the siblings of children with autism pose more problems needing professional attention than other children; and the extent their sibling's autism influences what they think about and worry about. We have tried to put experience into perspective and often say that "everyone is different" and we have tried to encourage positive interactions. (2003) Goechner describes siblings as "furthest thing from typical and wiser and more mature than their age would suggest". (2007) I would agree.

Animals

One counselor told me that my son was not empathetic and that empathy is very hard to teach. However, everyday my son views the weather and makes choices about how to care for the animals. There is a concern, empathy for them. Harry has always loved animals. He loved to play with stuffed animals, lining them up, carrying them around. Pets started with our dog, Murphy, whom at the time of Harry's birth was a 4 year old border collie. They met when I brought Harry home from the hospital. At 5 pounds, he was so very tiny in the car seat. Murphy smelled him and probably licked him, but he became Harry's pet, his companion and sleeping buddy.

Harry decided he wanted a hamster. He was about 4 or 5 years old. I told him he had to pay for it. We made a list of hamster needs (about $60 worth) and then we brainstormed ideas that Harry could do to raise the money. We called it the Hamster Appeal. We sent these ideas to family, things such as one dozen home-made cookies or a music video featuring Harry, and they obliged, and we spent a month filling orders.

After spending well over the initial $60 needed to cover the hamster costs and the costs for the cookies and videos, Bob, the hamster, came home to our house. Bob taught us more about Harry. Harry was very caring to Bob. He referred to him as part of our family including taking pictures of Bob for the holidays as we do as a family. He would set up a wreath or a Santa hat and have Bob's picture taken. Then he began questioning, "what will Bob wear for Halloween?" Harry preferred to be an animal for Halloween – a coyote or wolf, but a realistic looking one. These were not costumes found in stores so we would have to sew something for him. Now he wanted us to sew an outfit for Bob.

Also at that time, Harry started horse therapy and he continues riding today. Sitting on the horse was the first time he seemed calm. It was the first time I saw him with sustained engagement in an activity (not including sedentary activities like trains, cars and books). Horse riding also became the avenue to experience other challenges such as being in the rain. He was a member of the 4-H Proud Equestrians Program for years. Last year (2010), he competed with 'typical' riders for the first time and took 2nd place in horsemanship and 3rd place in costumes. In his 11 years, animals have been an integral part of his life:

Table 4: Harry's Animal interactions

horses

- horse therapy
- PEP
- 4H
- Horse owner

Farm animals

- Chickens
- roosters
- goats
- sheep

household pets

- Murphy the dog
- Fish and frogs
- Bob the hamster
- Cats including Geronimo
- Finches
- Button Quail

A recent article was written about Harry and 4-H:

> **4-H and its impact on one family**
> *posted on March 20, 2012*
> By Priscilla Martin
>
> What does impact actually mean? The usual definition involves the effect, impression, influence or force that something or someone exerts on something or someone else. This is one family's story about the impact 4-H has had on their lives.

Lisa Szymecko, wrote to tell us about her 11-year-old son, Harry, who has autism. At age 4, Harry began riding horses through the C.H.U.M. (Children and Horses United in Movement) Therapeutic Riding program. From there, Harry joined the MSU Extension4-H Proud Equestrians Program (PEP) and the Growing Together Equestrian 4-H Club which has members with and without disabilities. Harry, Lisa and Bonnie DePue, his 4-H leader, all agree these programs changed Harry's life.

In Harry's first year in the PEP program, he used a spotter (a volunteer who walks beside the horse and rider to assist with issues such as control, balance, coordination and posture). Then in Harry's second year, he rode without a spotter and he was selected Grand Champion (see picture right) in his division. This was huge in so many ways because, as Bonnie observes, the goals of these programs include empowering the individual to be victorious over his or her challenges; going as far as possible when he or she is ready; self-assessment and understanding that he or she has value that is not dependent upon - or able to be taken away by - others. By riding without a spotter, Harry enjoyed a rite of passage in that he did what his friends do without assistance. He was making changes in his life and doing so very quickly.

Although challenges remain, Harry is making great strides and not only in learning more about horses and riding, but in increased self-esteem, self-confidence, discipline and social growth. For example, for the past couple of years he has taken great pride in being a greeter for the C.H.U.M. spring gala dinner. He is also part of the integrated drill team that opens both the State 4-H Horse Show and The Ingham County Fair. At last year's fair, he took part in a costume class in which he rode his horse dressed as Rapunzel from the movie *Tangled*. Harry, himself, will tell you that, through participation in 4-H, his compassion has increased. Over the years, Harry has earned many ribbons for his achievements (including in 4 short years being selected "Young Rider of the Year"). However, as Bonnie points out, the importance is not in the tangible award, but in knowing that "who you are outshines all of that." Just being able to join in, play and share in a community where no disabilities or socioeconomic and political differences are noticed, Bonnie noted, is “a big deal.”

What’s next for Harry? He loves his canter and dressage classes and is intent on moving forward with his jumping skills. He is also planning to enter other categories (such as chickens) at this year’s fair. In addition, through Harry’s involvement in 4-H, his younger sister, Isabel (pictured left), has become an active Cloverbud (5- to 8-year-old member of Michigan 4-H). She greatly enjoys being a member of Growing Together 4-H and especially likes cantering on horseback, as well as working with chickens and crafts.

As Lisa sums it up:

"4-H has given Harry and our family (pictured belbow celebrating Harry being named Grand Champion) *the opportunity to participate at the level that met our abilities. It has challenged Harry and helped him integrate into the community. Inclusion is a big part of our philosophy and 4-H has done that!"*

What Bonnie sees as remarkable is that what Growing Together 4-H Equestrian Club is doing is still at the industry’s cutting edge rather than being routine. She credits this to the amazing partnership with Ingham County 4-H. As she wrote in a thank-you letter to the county:

"This could never have happened if you, our 4-H family, had not welcomed my students and our participation. You have not kept us at a distance or left us to be

> *a 'demonstration sport' but have made us part of and all that is special about the Ingham County 4-H program. You have not made us different; you have made us family and friends. . . . . [The resulting national and international presentations made about the partnership] is being used to help others nationally bring their riders into the 4-H family/local competitions in their own counties."*
>
> This story illustrates the profound transformational impact that land-grant education (as embodied in 4-H) can have on both individuals and society. Because of its unique combination of teaching, research and outreach, it brings the newest learning to all and, thus, is a dynamic, never-ending stream of information between those teaching, those conducting research, students and consumers.
>
> (All photos courtesy of Lisa Szymecko)

Because of the farm, Harry has struggled more with animals and their role in the family. When I started to give a chicken a worm I had found for the chicken to eaat, Harry was displeased. He hung his head and was rubbing his eyes under his glasses. When I pushed him to explain he said, "I don't know why anything has to die for us to live". He may as well have said any*one*. We talked about being a vegetarian. I have helped him identify other protein sources as alternatives to meat. "Hey, you have to at least try these beans, especially if you are not eating meat." At a baseball game, he asked if there was meat in hot dogs. I laughed and said that it didn't count if you were at the ballpark. I suspect he will continue to struggle with this and as he is more able to dictate his food choices, will opt out of meat.

Farm

In this section we transition from owning a farm to becoming active in the community to building a farm for others.

Finding the Farm

The summer of 2006 was so hot and sticky. We lived in a 2-bedroom cottage on a lake, which sounds cool yet the neighbors had just finished building a monstrous house right on our border. When our phone rang, they went to look for it. When their garage lights were on, I had to close the living room curtains. Their hot cement driveway radiated the summer heat all night long. I remember that both Joel and the kids were home sick on a summer Friday. So, on this hot day, I decided to take everyone for a ride (in air conditioning). To make it interesting, I plotted a route that took us to five farms for sale.

We had never considered buying a farm but the idea had started to percolate after seeing Harry's success with horse riding and his need for heavy work. A farm would allow him to integrate therapy in his daily life. With a better understanding of his needs, a farm seemed like an opportunity to provide an outlet for him. However, we had to be able to afford it and it had to have been used as a farm – which also meant the farm had to have out-buildings.

When we pulled into the drive way off of Noble road, I roused the kids. They were excited and ran off to the barns which were filled with cats. The circle gravel drive reminded me of my Aunt Bessy's farm. The birch tree in the center of the circle looked like the birch tree in the front yard of my mom and dad's house in suburban Detroit. Harry named the four cats that he found within minutes: Smokey, Mama, Mittens, and Misty and assigned each one of us a cat – Smokey was his, Mama was mine, Mittens was Isabel's and Misty was Joel's.

The house was empty and the price had been reduced. With creative financing, we were able to purchase the house. After we closed on the house, we took the cats to get fixed. Smokey already was. Misty was a boy, Mittens was a girl and Mama was pregnant. Within one month Mama had four kittens: Geronimo (Harry's kitten), Tinkerbell (Isabel's), Anne (left and returned de-clawed) and one that had a permanent placement.

We moved into the house with our other animals too including Bob (hamster) and Murphy (the dog). Soon we had fish. By October we had goats (thanks to a house warming present from my sister). In May we had two therapeutic riding horses. By June, we had a thoroughbred horse. The farm was amazing. Harry was hauling hay and water to the horses and goats twice a day. He could swing or jump on the trampoline. He could explore the creek, climb a fence, run in the fields, or hang from a tree.

The farm is a just under 10 acres. It includes my house, a creek with a bridge, three out buildings and chicken coop. There are five separate fenced pastures and a dressage field between the front of the house and the creek. The garden is located behind the house, next to the two pastures. My favorite description of the farm is the "horse farm on the hill". When I am outside looking at the failing fences or peeling paint I remember that description and smile.

Looking Up

I finally felt comfortable about Harry and I could finally look up and reach out to others. My first email went to those at MSU whose name came up when I googled "autism". My email is below (November 2006)

> I have been at MSU since 1998 as an employee (CEE and Extension) and now a PhD student. My son (6) is autistic. Since his diagnosis over 2 years ago, my husband and I have been on a steep learning curve not only with his disability but with the system and the school system. I was wondering what MSU's involvement is with children with special needs, the families or their communities. I have failed to find a cohesive structure in Mid-Michigan to meet his needs. I see that some communities have received funding for this type of assistance.
> I would be very eager to discuss my findings with you or assist in any way if this is an area of growth for your organization.
> Thank you
> Lisa Szymecko

To all of those I sent the email to, I received this one positive reply:

> I would love to get together to talk. I am in MN next week, Traverse City the following and then to visit my mother. How does early December work for you? Esther

One very interesting email stated:

> Dear Lisa - I am no authority at all on autism. I participate in a very small way on a data management project that coordinates information collected in autism centers nationally that we have at MSU. However, on Th April 12th at 4:30, our seminar speaker in epidemiology is Jennifer Pinto-Martin who directs the autism center at the University of Pennsylvania. She is an epidemiologist, not a clinician, so cannot provide you information relevant to your son specifically, but I think she will review what is know of autism frequency and risk factors. The seminar will be in the Patenge room in East Fee Hall.

The email above was from someone with these credentials: Professor of Epidemiology and Pediatrics and College of Human Medicine with an MD (Harvard) and MPH (Columbia) and has written extensively on autism including his latest three articles on autism:

- The Effect of Gestational Age on Symptom Severity in Children with Autism Spectrum Disorder.
  Movsas TZ, Paneth N.
  J Autism DevDisord. 2012 Mar 16.

- Prevalence of autism spectrum disorder in adolescents born weighing <2000 grams.
  Pinto-Martin JA, Levy SE, Feldman JF, Lorenz JM, Paneth N, Whitaker AH.
  Pediatrics. 2011 Nov;128(5):883-91.

- The Modified Checklist for Autism in Toddlers in extremely low gestational age newborns: individual items associated with motor, cognitive, vision and hearing limitations.
  Luyster RJ, Kuban KC, O'Shea TM, Paneth N, Allred EN, Leviton A; ELGAN Study investigators.
  PaediatrPerinatEpidemiol. 2011 Jul;25(4):366-76.

So, the doctor was not an expert. But Esther was willing regardless. I was curious. Esther and I met. She was a mother of a son on the spectrum, only he was about 13 years older than Harry. One thing was clear: times have not changed (enough). We formed a group for others on or near campus: Families of children with autism. Here are my observations from the first meeting:

- There is an interest in a support group
- Ranging ages and school districts and families
- Value of meeting/communication/listening and sharing
- Interest in a list serve

- There are commonalities and differences but awareness is needed
- Community is key

MSU set up a list serve and hosted brown bags for us. We held events including a large picnic at a park. It was an opportunity for people to share in a safe environment. “Safe” meant free from judgment because this was a group that understood differences. Picnics and group activities can be stressors, but given open space and forgoing the requirement that everyone has to sit in the pavilion, then families are much more able to talk. There were people on the swings, a few walking around the pavilion, a few, especially siblings, doing crafts in the pavilion.

Meeting with other families I realized I had similar frustrations and yet I also realized I was in a place that I could do more for others. I had support; I understood the issues; and I had Harry.

So, in October of 2007, I held an open house at the farm:

Figure 5: Open House Invitation

Families of Children with Autism
Potluck Social

The support network for MSU parents of children with autism will be having a potluck social on Saturday, October 27from 1:00PM-4:00PM at the “Farm” in Williamston. Bring your families and come to meet and have a great time!

We look forward to seeing you there!

Date: Saturday, October 27, 2007
Time: 1:00PM – 4:00 PM
Location: 3639 Noble Rd, Williamston
Home of Lisa Szymecko, Joel Wallace, Harry and Isabel (plus horses, goats and chickens)

Directions from campus:
96 East to Dansville Exit. Turn Right onto Williamston Rd. First Street is Noble, Turn Left on Noble. We are the Second House past Dietz

RSVP
Call: Lisa or Joel at 517-214-00XX

To be added to the listserv for parents of special needs children, visit the FRC website or call!
http://www.frc.msu.edu/listserv.cfm

The open house was very successful – there was a good crowd with some that I had not met. Many sat around the dining room table. I know Joel and I spent most of the time separately helping individuals see the farm, animals and Harry’s bedroom, and not so much ours. There seemed to be a need to talk and a desire to do more. So, we organized an Art Show at the local coffee shop. The art show would be in March but someone in our group organized an art session at the Kresge Art Museum. It was amazing!

Figure 6: Art Session Invitation

MSU Families of Children with Autism are hosting:

A Special Needs Art Session

The support network for MSU parents of children with autism is hosting a Special Needs Art Session for children and adults on the spectrum.

Date: Saturday, December 15th
Time: 10am - 12pm
Location: Kresge Art Building at Michigan State University.

The program will connect artists on the spectrum with MSU Art Education students. It is not open to the general public. Art made at the session can be used for the *Art on the Spectrum* art show at the Cappuccino Espresso in downtown Williamston. Registration is required.

To register for this event:
Visit: http://www.frc.msu.edu/registration.cfm
Email: harri474@gmail.com or Call: 432-3745
Family Resource Center, 225 Nisbet Building

To be added to the listserv for parents of special needs children, visit the FRC website or call!
http://www.frc.msu.edu/listserv.cfm

My original idea was for individuals expressing themselves with their own art work – perhaps something they already had at home. But the Kresge Art opportunity allowed the artists to learn some new methods, engage with others which included siblings, and create something new. It also was a way for college students to meet this population. The MSU art students came to the opening of the art show at the coffee shop. That was pretty cool. Many of the artists feared the potential crowd so they did not want to come to the showing. We worked with the shop to have an hour of limited crowd time. That was nice. The students were as proud and pleased as the artists. I think Harry ate 20 cookies.

We also opened the farm to Izzy's preschool class. It was a weekday and both Harry and Isabel were home helping me get ready for her class's field trip to her house. As I was getting the animals ready, I noticed a raccoon in one of the pastures, not looking so well. Actually he was injured and not moving very much. A suburbanite, I called animal control. They were not coming over, even if in a few short hours I would have a farm full of4 year olds. They said to shoot it. I was shocked and blurted out that I didn't have a gun (instead of saying I would not shoot anything). He then asked if I had a shovel. I could hit it on the head. I hung up. I called a local vet to see if I could take it there. They did not want a rabid raccoon either. I called Joel (at work). He came home right before the preschoolers arrived. He told me that by the time he came home, the raccoon had already died, so he buried it. Years later when I asked him about it – he just gave me a look like "you don't still believe in Santa".

It was also on this day of the field trip, an older brother of one of the preschoolers came to the farm too. He hit it off with Harry. Those two spent most of the day together with the animals. I saw behaviors with this young man that was similar to Harry's, so afterwards, I sent a message to the school offering my contact information if he had an interest in talking. There was. I was right. The farm is a good place.

Organic Growing

We started thinking about organic farming. Our neighbors had stopped by when we moved in and offered to give us a hand the following spring. In an email dated 2/11/07, we asked for their help:

> Hello,
> We are the family at 3639 Noble, and hope you have been well. I know it's been a while since you stopped by, but we have kept your card on the fridge.The note mentions contacting you in Feb about seedlings and we have acouple questions. I know you start tomatoes, but I can't remember if you start any other plants. We are interested in tomatoes, but also other vegetables.
>
> We also wondered if you would care to get together and talk about gardens. We think we have space to plant, but don't know too much. We may have more space that we can take care of. But we were hoping we could talk.
>
> We hope to hear from you.
> Best wishes.

We had gardened before, in Chicago, on a plot next to the garage – probably close to 4 ft x 8ft. Our Chicago experience was that people lived close together but did not really talk or know each other. The garden changed that. Seeing corn grow a block from Wrigley Field brought out conversations across the fences. We also had a small garden at the lake cottage. Joel had made two plots so that we could walk between them. From the road they looked like graves. We planted the garden at the lake house together and that evening, my water broke and Harry was born the next day. Therefore, the garden at the lake house received very little attention. So, now with the farm, we had plenty of space to garden and our neighbor was very helpful. He provided transplants and a planting diagram; advice and tools. Excerpts from emails from them:

> I have attached a Word document which we use to put seed orders together. It shows what we grow and the varieties and approx quantities of each. You can see where we have designated transplants for other people. The same document has the garden layout. For your first year, that's at least twice as big as you would want to go with.

or

> Instead of renting another tiller you should just call me and I'll bring ours over. We have a 8-hp Troy Horse which is probably bigger than what the rental place carries and it will take care of the sod area.

We did rent a rototiller and it broke. Joel tried to rototill a circle around our flag pole but for every minute it worked, it took 15 minutes putting it back together. At the end, I remember Harry looking out from his second story window and saying "Hey is that supposed to be a circle?" (It was). Our neighbors came over to give us transplants but after they saw what we had done, he ended up walking his rototiller to our house. It was dark rich soil and the tomatoes, green peppers, and onions eventually grew like crazy in that plot.

Gene, our helpful neighbor, was also a source of information

> Organic chicken feed. The only source I know of in the state is Craig Kovacic (KOH-vah-see), near Imlay City. He is president of Organic Growers of Michigan (now largely a defunct organization). Google "Organic Growers of Michigan" and his phone number, email and address should show up. Most of the other people I know who are doing organic eggs or chicken make their own feed, or buy it from Craig. Pooh Stevenson, on West Main Street in Owosso (she has a CSA, and usually sells at the Meridian Township Farmers Market on Saturday), may have some ideas.

Chickens

After we moved to the farm, Judy (an Admin Asst that works at MSUE) said that we should split a bunch of chicks. Judy has been ordering chicks every couple of years, for quite some time. It is a hobby. She uses the eggs and she likes the different looks of the breeds (and their eggs). Using the McMurray Hatchery catalogue, she ordered 25 one-day old chicks, all different breeds. Soon after they arrived at her house, we drove over to see them. They were so very cute! She showed us how to care for very young chicks (feed, water, heat). When they grown a little and were not so fragile, we brought them home. They lived in a cage and dog house until we built our first chicken coop.

When we brought the chickens home, we named them. Mine was Blue – a lovely blue cochin with feathers on her feet. Joel named Hawk and Granderson. Izzy named Beauty and Snow White. Harry named Tiger and a big Rhode Island Red – Ginger, and my dad named the Polish crested chicken – “rooster” because he thought it was funny. As a first generation Polish-American, he said “well, if it is a Polish chicken – then it is a rooster”! The funny thing was, that chicken did grow to be a rooster. It was a bit crazy with its white feathers hanging down in his eyes. He could not see that great and sometimes thought the food dish or the minivan were “threats”. He would crow morning, noon and night. If we drove up late at night, he would crow. He became the name sake for the farm – Polish Acres. The name is a little about our crazy first rooster, a little about our heritage, and a way to also remember my dad who passed away after a year at the farm. He was 88 when he died, but the funny thing is, he said he loved the farm and wished he was 20 years younger so he could be more helpful. We laughed! I said it would be better if he was twenty years younger than that!

Harry added a second rooster, quite serendipity: He wrote a story about it for school. In “Friends of a Feather”, Harry wrote

> “One ordinary day riding on the bus, Harry learns that a rooster is stranded by Linn road. He and his Dad set out on a thrilling and epic tale of bravery.”

For all the animals that passed away, including chickens, we buried them, often in the front yard or near their favorite part of the yard. It seemed a bit strange but Harry never wanted them to be alone or far away. So, even with acres of land, the animals were buried near to the house. I never said much about that to others, because it seemed a bit strange, but in talking with Esther, she mentioned that they too bury their beloved pets in the front yard. I know this is not any indicator of autism, but as mothers, we understood.

Putting the "Social" into the Farm

So, I had this idea that if the farm was good for Harry and others, I should do something about it. It was Esther I told first and she reminded me of the history of farming with people with mental illness and that there could be stigma attached. I googled it. I could not believe it. There were other farms for those with ASD. I was so excited and then I was "hey, why didn't I look this up before? That was do dumb." But I contacted them, told them about my venture and signed up for their newsletters. Bittersweet Farms in Ohio and Full Spectrum farms in North Carolina were the most supportive. They offered to meet to talk or whatever I needed.

A list of farms I found in North America and overseas is in the table below:

Table 5: Farms for those with ASD

Farms- United States	Location
Bittersweet Farms	Whitehouse, Ohio
Mandy's Farm	Albuquerque, New Mexico
Full spectrum farm	Cullowhee, North Carolina
FAP: Friends of autistic people	Shelton, Connecticut
Camphill Village	Copake, NY
Safe haven farm	Madison Twp, Ohio
Gottschall Center	Mattapoisett, MA
SAGE Crossing Farm Program for Autistic Adults	Concord, MA
Countryside	Fayette County, Texas
The Hiram Farm Living and Learning Community	Hiram, Ohio
On greener grass	Watsonville, CA
Farmsteads of new England	Hillsborough, New Hampshire
Tranquility farm equestrian	Thurmont, Maryland
Carolina Living and Learning Center -	Pittsboro, North Carolina
The Homestead -	Runnels, Iowa
Carolina Farm	Albermarle, North Carolina
Rusty's Morningstar Ranch-	Cornville, Arizona
Roses for Autism Pinchbeck's Rose Farm	Guilford, CT
Grisham Farms	McKinney, Texas

Table 5 (cont’d): arms for those with ASD

Lovewell Farms (attempt at a farm but due to funding and expertise – did not develop)	
Rockwood Farm	Adrian, Michigan
Pheasant Ring	Rochester Hills, Michigan
Adonis Family Farm	Florida
Farms – Worldwide	Location
Somerset Court	Somerset, England
Pennyhooks Farm	Oxfordshire
NyAllerodgärd	Alleröd, Denmark
Dunfirth Autistic Community	Enfield, County Kildare, Ireland
La Pradelle	Saumane, France
Hof Meyerweide	Bremen, Germany
Farmstead in Netherlands	Wolfheze, Netherlands
La Garriga	Barcelona, Spain
ArionTheraputic Farm	Kelowna, Canada

How could there be so many farms, and so little data? And this was a preliminary list. I struggled with my own identity and pull to create the farm. I did not think I could both start a farm and write a separate research dissertation. I paced the bathroom quite a bit.

Changing my Dissertation

A big part of the journey to the farm was the change for me. Below are two pieces I wrote specifically about my own perspective on “what is knowledge”. In 2004 I began to formally question (it was the start of my PhD) and by 2009 I had transitioned.

In September 2004, I wrote:

> The Path of Knowledge
>
> I never questioned the scientific method of knowing and I only valued knowledge that was based on “real” science, not the soft sciences. This was based on my training as an engineer and not on any philosophy class. In fact, the only philosophy class I had in college questioned what is human and compared humans to robots. I remember that our tests were scan-tron. My boyfriend at the time (and later husband) at the Jesuit school of University of Detroit, scoffed at my lack of knowledge and non-exposure to the masters. I argued the scientific method of knowing then, without even knowing that I had backup with Thales, around 600 B.C., the Pythagoreans a hundred years later, and Plato and Aristotle. The modern scientific method, based on observation, mathematical measurement

and description, and logical analysis, owes much to Galileo and his contemporaries Francis Bacon, and Rene Descartes.

I realize that is time to broaden my view of knowledge. I am not ready to abandon the scientific method even with the inherent problems with dualism. Perhaps I am seeking an advanced degree outside of the “real” sciences because I agree with Weber"[w]ith the progress of science and technology, reality has become dreary, flat, and utilitarian, leaving a great void in the souls of men which they seek to fill by curious activity and through various devices and substitutes."

So, what is this path to knowledge? How do I overcome my love of objectivism and epistemological anxiety?

Whitehead indeed laid a strong argument against objectivism: adopting the weakest side of science; mistaking abstractions for brute facts and then rectifying these abstractions; applying an inappropriate test of "truth" to these abstractions; adopting a hierarchy of reality that identifies the "facts" with knowledge of those aspects of reality that enjoy simple location while dismissing modes of knowing appropriate to other aspects of reality as inferior. How often have I dismissed the knowledge of others because it was not based on science or how often I have tried to add more “scientific analysis” to writings from the field so that they would be more accepted by peer review, instead of more accessible and understandable. Why do I push for a language that is in isolation to others?

Perhaps Wittgenstein, a man after my own heart (trained as an engineer), can help me overcome my anxiety and move on. He believed that objectivism was too simpleminded, too narrow, too limited for the larger meanings of life. If that is the case, what can I use to fill the gaps? Does Habermas have the answer in his democratic approach?

Habermas defines three forms of knowledge as empirical analytic science, intersubjective understanding and emancipatory purpose. Can I embrace intersubjective understanding? Is this really “woman’s intuition”? I am not comfortable with gap filling scientific method with intuition. Is this the anxiety I was trying to overcome?

Revisiting intuition as based on total life experiences; knowledge from formal training and life experiences combined may be a gap filler, albeit an uncomfortable one. However, I do see emancipatory purpose as a gap filler, a form of knowledge although put forward in a historical context, can apply today. The strive for freedom of thought is universal and whether political or social, can strive to fill the gap of knowledge.

So, have I completed the path of knowledge? Have I moved along the omega? Actually, I did my approach may be more of a upsilon or a gamma (but not a sigma!)

In the midst of my PhD program, I changed my advisor. It was unexpected but I remember sitting in his office when he told me that I did not have any skills. I realized it was never going to happen with him, so I fired him. I took the summer off to see what I really wanted to do. It was the farm. Dr. Laurie Thorpe spoke in one of my classes. In the hallway outside of class, I told her about my son and my desire to do research and start my farm. She didn't even blink. She said that it would be a wonderful project. Later, she found me through the course instructor and offered her advice through email. So, in 2009 I wrote about my transition (part my paper is below):

> Transition in Research and Methodology
>
> This paper is a very personal process of change that started last year and has solidified over time. This change was a movement away from traditional scientific research to a participatory action research methodology for my own dissertation research. The change was from an expert observer to an engaged human.
>
> The Dark Ages
>
> My dissertation research initially involved environmental risk and community development. My work was to be predominately quantitative in nature – studying environmental models of risk in a variety of community settings and considering the economic and legal aspects of the policies surrounding environmental remediation and risk. Data collection (soil measurements, chemical properties, routes of exposure) would be obtained as well as the legal and economic data and demographic data surrounding the contamination. As stated by Faye (in Fischer), my approach assumed that the positivist method was the only valid means of obtaining true knowledge (Fischer, 2000). An objectivist, reductionist view, I would calculate the risk standards to the community and use the standard form of risk communication explained by Thompson where I attempted to bring the community "in-line" with the experts (Thompson, 1999).
>
> From my standpoint of objectivism, all nonscientific modes of knowing had the status of non-knowledge (Yankelovich, 1991). I failed to follow Habermas when he defined three forms of knowledge as empirical analytic science, intersubjective understanding and emancipatory purpose. I did not believe that intuition was a valid form of knowing and believed that my work should be divorced from any value judgment (Masters, 1993).

As I began to reflect on this work, I wanted a more systemic approach where ethical, aesthetic, spiritual, cultural and ecological criteria were as important as the technical and economical criteria. (Bawden, 2000) I could choose a more holistic approach to the remediation, an ecological view (Jackson, 2000). I thought that any discussion of ethics or morality would reduce my professionalism instead of showing my humanity. I now agree with Wittgenstein that objectivism was too simpleminded, too narrow, too limited for the larger meanings of life (Devlin, 1997).

Enlightenment

Most feminist researchers have long since agreed that there are no specifically feminist research methods. The expression "feminist research methods" is therefore used as shorthand for methods used by feminists in all fields of research. However, there are common characteristics of feminist research: it has reflexivity; an action orientation; attention to the affective components to research and use of the situation at hand (Fonow in Kirsch p3). I wanted my research to be introspective and have the ability to adjust my research goals and I wanted to create change, especially in the lives of women. I also wanted to incorporate many ways of knowing, including the emotional dimensions and use everyday events to "acknowledge the significance of daily lived experience." (Id.)

My foundations for feminist research methods include my own skepticism on claims to objectivity, my movement away from positivist methods and my interest in supporting different ways of knowing including perception, emotion, reason, and language. My epistemology for my dissertation is based on a situated knower. I believe we all have partial knowledge based on who we are and are own experiences.

Applying feminist research principles just does not seem to be enough, however. I felt the moral obligation to make a difference by my actions but also to embrace my passion. But by moving away from the science – am I just another statistic? A feminist empiricist would argue for more women to remain/be brought into the scientific world. Would my leaving the science field further reduce women's perspective? Do I have a duty to study environmental contamination using feminist methodologies due to my unique standpoint? I have a double perspective that can offer more insightful and more complete interpretations – as a scientist and also a woman (marginalized). (Kirsch p.15) `

My new research embraces situated knowledge. It accepts the subjectivity of research and the researcher (me)! (Haraway, 2001) I have decided to move away from my dualist life and merge my professional and my personal interests. They could never really be separated anyway.

New Research Topic

> My topic areas include community development and sustainable agriculture using feminist methods and participatory action research. The purpose of this study is to construct an understanding of the impact of a community farm on the farmers, their families and the local community. The farm is inclusive as it will reach out to families with those on the autistic spectrum. It is common that families with individuals on the autistic spectrum are led by single mothers. This study will give farmers the opportunity to participate in agricultural activities (building, growing, crops, animals) that they have an interest in pursuing. It is under the philosophy of praxis (practical application or exercise of a branch of learning) that farmers will decide how this community will develop, grow, learn and change.
>
> Farmers are defined as everyone who participates in any way with the farm – from those that believe they are advisors, to educators or workers. There is no separation by class or abilities because the farm exists because of everyone's engagement.
>
> (continued)

I was growing as a person. I was developing my own program. I was using my voice. I was taking very different ways of knowing and incorporating them into my own. I was listening to doctors and therapists but I was also observing and making choices on a combination of some well researched and some intuitive information. And I was treating them equally.

My committee agreed to stay with me despite the change. Peter agreed to be my advisor. In December 2009 I took my comprehensive exams and tried to write a proposal. But in 2010 we were struggling with the house payments. Joel had lost his job in the year before and it was replaced by a job with half the pay and little benefits. But it was a job. Discussions with the bank promised that we could do a mortgage modification and it would be resolved by May. With daily calls to the lender, it still lingered until October. But I believed in the farm and I could see the positive evidence every day. We tried to maintain a level of normalcy and I tried to start the social farm – as crazy as it sounds.

Social Farm Year 1

J, another helpful neighbor, drove his tractor over to plow for us. This would be a bigger area that we could rototill. I was excited but I also had our predicament with the house in my head, constantly. I pushed forward on living, but felt a strong and heavy weight of the unknown. I stood outside watching him plow, hopeful and thinking “we did it”. We may lose it tomorrow, but we did it today. We gave him gas for the hour long tractor ride home.

Now, we had an open spot. We were ready but I was so very uneasy about asking people to come and I was so unsure. Harry changed that. His birthday is the end of the month of May. He wanted a sit down fancy dinner, which we obliged in the living room. A long row of tables and an eclectic mix of chairs and benches completed the dining space. After dinner, Harry wanted everyone to plant. I was reluctant but we had seeds. Harry assigned the seeds to whom he thought was an appropriate match. We all headed outside to the freshly plowed area, and planted. Grammas, aunts, uncles and cousins all planted rows of seeds. My body was so incredibly stressed but here we were, planting, when I could never have imagined. Only one of my sisters knew of our house issues, and maybe not to the full extent. No one else knew anything about our problem.

Planting inspired me so I contacted G for transplants and sent out a flyer:

6/3/10Invite

You’re invited to our Farm for families and individuals with autism.
- Do you have a son/daughter with autism?
- Would you like to be a part of a pilot project where we will work on the farm, join in
educational opportunities, and earn a share of what we produce?

Please come to our Farm Open House
Saturday, June 5 from 1:00 pm to 3:00 pm.

Learn about this opportunity and come and plant with us. Be a part of a local food movement.
Connect with others. Experience farming.

This is a working farm. We have an area tilled for growing vegetables and flowers. We will be
getting chicks soon. We have goats and sheep as pets. We will set up farm working hours and
monthly workshops depending on the needs of the participants.

Our story:

> *My son, Harry, is on the spectrum. We wanted to integrate his therapy into his natural daily life. So, we bought a farm. For the last three years, my son has been hauling hay, mucking stalls, feeding and caring for chickens and goats. He has hauled soil and compost with wheel barrels. He has planted corn, cucumbers (loves pickles), tomatoes, squashes, eggplants and other items. He harvested wild blackberries for jelly, apples too! He is connected with the land and the animals here. One counselor told me that my son was not empathetic and that empathy is very hard to teach. However, everyday my son views the weather and makes choices to care for the animals. There is a concern, empathy for them. Now we want to make our farm open to others.*

Please contact Lisa or Joel at 571-521-XXXX or email joel.p.wallace@gmail.com orSzymecko@msu.edu if you have any questions or are interested but cannot attend on Saturday.

Our farm is located at 3639 Noble Rd., Williamston (between Dietz and M52).
The bridge is out on Noble between Williamston and Dietz.
We hope to see you on Saturday!

We had a great turn out. Many families from came throughout the day. We talked about the ideas and the plans as we planted corn and tomatoes and pickles. People we didn't know came too. It re-affirmed my belief that this would work and needed to.

At the time I was working multiple jobs with the one farthest from home located in Flint. My mother and niece were staying at my house to care for the kids. It was wonderful and stressful rolled into one big ball conveniently lodged in my stomach. As I would approach the house, I feared there would be a yard sign that said "house in foreclosure" or "bank sale". I know we were in the modification process but depending on who you spoke with from the bank – you could get any number of responses on any given occasion and even on the same day.

Given that framework, I tried continue the farm but had a hard time scheduling in advance. This left little notice to those that wanted to participate. I was very apologetic, felt like a failure for many reasons, and by the end of the summer let most of the farm become overgrown with weeds. However, I would say – this is not a failure. We got it plowed and planted and held an open house. We have some tomatoes and peppers. Just wait until next year.

Social Farm Year 2

J asked about plowing again this year and we happily said yes. This time, there was a little more of a celebration with a few cold beers and cash (for last year and this year). It represented a lot for me. The stress of losing the farm was over. We made it as an intact but bruised family. We had hope for the season and no more fear of yard signs. Maybe we may just put up a Polish Acres sign. But then, I didn’t want to jinx it.

With the ground plowed into lumps of grass, it was time to open the doors for the summer. I did not go with the flyer. I was going to work with a small group of forgiving families and grow by word of mouth. With my job in Flint the summer before, it was too difficult to schedule days consistently and that made it difficult for everyone. I also know that I did not have air conditioning in the car, nor working windows, so by the time I made it home (about 1 hour drive), the heat had drained whatever energy I thought I had.

This summer was going to be different. I was only working 20 minutes away, even though it was the same hot car. So, looking at our family’s schedule, we picked Tuesday nights and figured it could change to meet the needs of those interested. So, I sent out letters to people and parents that had expressed interest in the farm and/or had come out last year. An example of a personal letter to a mom is below:

Email on 6/6/11

> Hi B,
> I wanted to invite A to participate on our farm. I am an advocate of social farming – the idea that people benefit from more than just the good food grown on a farm. I have an area plowed and have a couple of folks that – as we work together and plant – will share in whatever comes up and maybe have a good time doing it! We are going to get started tomorrow (Tuesday) about 5:30,. This is informal and people can engage in as much (or as little) as they want. We have the chickens too – and will probably get some more (oh, we use the eggs).
> Let me know if he needs a ride - we live close (3639 Noble).
> Thanks
> Lisa Szymecko (Harry's mom)

That first evening I was so nervous. I was not sure who or how many would show up. We set up a table and chairs by the garden and had bottles of water. I wanted all of us to be in the garden when anyone arrives. I wanted to make sure and greet them. I spoke with the kids about welcoming each person. There were a few last minute calls and I set the cordless house phone on the hood of the van. That was the last time I saw the phone, ever.

We had a great turnout. We had 4 young men with ASD, a grandmother, Isabel, a Speech teacher, and a sibling, plus my niece and my mom. We worked on introductions. Harry had a book. Then Isabel and the sibling took off to the house.

They all looked at the large lot filled with grass lumps. It did not look all that great but I had an idea. I asked if anyone would like to drive the lawn tractor (blades not spinning) with a rake attachment. Everyone wanted to drive. So we used the garden tractor to rake the garden and try to clear some of the lumps of grass so that we could get something into the ground. I still was not sure that was going to work because of the noise but each young man wanted to drive it. They took turns, they wore headsets and the drove it back and forth in a variety of gears. While waiting for a turn, there was a lot of discussion about the tractor and their turns and

I reassured them that they each could drive it (again). It felt like a sense of excitement was rising with each opportunity.

I had a goal in my head to get something planted, anything. But I did not have all the transplants. So, Joel took one young man over to G's house (in the van) to pick up transplants that he had started. G offered to give us his leftovers – whatever he did not get planted. G got to meet one of our farmers and our farmer had the opportunity to visit his greenhouse. I lost my phone.

For those of us who remained in the garden, we placed walking paths down using old horse feed bags. Then the wind blew and we lost our paths. A bit of wire would hold them down so we used a punch to make holes and bend the wire into the ground. This was detailed work. We set up an assembly line – bag –holes-wire. Repeat. When I looked up, one young man was petting a horse. I couldn't blame him. I asked what they wanted to plant. One said "food". I think he was very optimistic. We made a list.

Paths in place, at least some of them, we needed to fill the squares with compost and newspaper. Two young men, using a wheel barrel and shovel went to the compost pile – chatting. One young man and I were placing newspapers down when the wind blew. All of us went running to catch the papers. We had to wait for compost. Those two were talking more than filling that wheelbarrow! More than one boy dumped a wheelbarrow before it made it to the garden. It was a slow process, but with social farming, you have to know that efficiency is not the goal, at least that was what I kept telling myself.

As I looked around, one young man was sitting in a chair with Harry's book. The others were a bit confused by this process – no one had ever planted before. But the paths were a clear visual. The newspaper would help us reduce the weeding. Isabel and the sibling hauled the hose to water the garden.

It was starting to get a little dark but the worst thing was the mosquitoes. They were out with a vengeance. The wind had stopped. We sprayed each other with insect repellant but it didn't seem like it helped at all. My goal was to get something – anything - into the ground. We did. We ended by 9 o'clock, tired and mosquito bitten. I sent out the following email:

> **6/8/11**
> WAY TO GO Farmers!
> Even though we had the battle of misquotes – the squash and a tomato made it into the garden! YEAH!!!
>
> That was after the tractor raking (nice driving everyone), building the path (ok, so they are old feed bags and some say buckeye – we can walk on those HARDER), and getting some compost down.
>
> Harry will be busy watering and I will pick up those other items that you guys wanted to plant: carrots, cantaloupe, strawberries, corn, potatoes, watermelon, pumpkins, and whatever else was on that list.
>
> Hope to see you Tuesday, June 14. I will try to be there by 5:30.
> Cheers!
> Lisa

The next Tuesday night was easier. We set the chairs and umbrella up at the edge of the garden. I brought out some water bottles. When people came, there were smiles and walks around the garden on the horse-feed-bag paths. We were all getting to know each other. The night was a big planting night. Joel and another young farmer went over to G's to meet him, see his greenhouse, and bring back more plants. We had a good turnout, including my niece and my mom. I also received emails from parents, wanting to come but scheduling was difficult – it was not that it was Tuesday, but that it was another obligation and transportation showed the first signs of clearly becoming an issue. I offered rides either locally or from MSU.

We spent most of the evening planting sections of the garden. Farmers wanted to identify their own plant –"I planted this one" or the section. Although the garden was planted collectively, there was ownership. Everyone got their hands dirty planting the transplants from Gene. We had peppers, eggplants, squash and kale. We would decide what would be planted and where (what section). Standing in the garden with a table with the plants and seeds on it, I would ask where the peppers should go and someone would say "right here" and all of us would think about it and give an opinion. I would say "who would like to plant it?" When that didn't work anymore, I would have them look at the table and pick out what they would like. All the plants and seeds had a photo of a grown plant. If someone wanted to plant something specific, they could show where they would like to plant it. We would talk across the rows about how to plant, how deep and spacing. But I was very conscientious of not making it hard. My niece planted rows of onions. She would ask me if it looked right. I assured her that you can't hurt them. She was a much faster farmer than anyone else. My mom, on the other hand, was sitting in her wheelchair giving advice to the group like "don't plant them too close". She would also comment on how others did like "he is a hard worker". So there was an eclectic mix of farmers: sometimes talking, sometimes swinging, and sometimes sitting with a book (if my mom allowed it!) My email is below:

> **6/15/2011**
>
> Howdy Farmers,
>
> What a beautiful evening to be outside. Less misquotes and a nice breeze. The horses and goats were just hanging out watching us. We got so much planting was done – onions, peppers, eggplant, tomatoes, and swiss chard. We moved the old swing set over (without the swings) and using some twine, made a trellis and planted cucumbers on one side and zucchini on the other. Everything was watered using the hose and/or watering can.
>
> We have some more plants from our neighbor G and we have some seeds that we just didn't get to last night. Maybe next week we can plant those. I want to also

> try the potato planting in a bucket. If anyone has old potatoes (with eyes), bring them next week.
>
> When I went to pick up N yesterday, he didn't want to garden so he wrote a note saying "I quit. N". That is a great reminder that Tuesdays are meant as an open farm day and that you can come or "quit" for any day. Of course we miss you but there is always the next week. That is one thing about farming – there is always plenty to do.
>
> Speaking of next week – I would like to put the chickens in the garden next week. Many of you have not met all of our hens. I think it will be fun!
>
> Thank you Matthew and Rich for hauling compost and Emily for helping with the onions (even though you don't like to eat them)!
>
> Hope to see you Tuesday, June 21 at 5:30ish.
> Cheers!

The next week it looked like rain, so I sent out an email that we were still going to have farm night. I wanted the farm to have a consistent night, no matter what. I wanted that for our family schedule and to show our commitment, as well as for the structure that provided, especially to those with ASD. Knowing farm night was always Tuesday, families like ourselves could put it on the calendar, talk about it, and prepare for it. Transitions and new activities can be difficult. There may be a reluctance to move from one activity to another. Coming to the farm, working, being outdoors, may be a big step from video games or TV so there had to be enough structure and preparation for it to work.

Transportation was clearly a big issue and we offered rides. It was difficult for families to come to the farm – the entire family. It was time consuming to even do only a drop off and pick up. There was not complete interest in families to stay. There was a voice of leaving their child and or sibling at the farm "are you sure it is ok?" But with that said, parents did not stay.

6/21/11

> Howdy all!
>
> Hope to see you soon! If we get some rain, we will spend more time with the animals. The chickens like the indoor arena too!
>
> Lisa

We didn’t see any rain so we had a great night out in the garden. Attendance was good. People pulled their cars around the birch tree loop and came right out to see how things were growing. At the beginning I asked if anyone wanted to get the chickens. Harry and Izzy and two others ran to the coop. The others looked at me and I said “Go and get them. They are friendly.” Harry and Izzy and others would show each other how to pick them up. Then the chickens were carefully carried to the garden with giggles and flapping and happy sounds by kids and birds. The chickens were happy to be in the dirt, which was full of bugs. There was a lot of fuss by the farmers at which section the birds should be in and whose plants they were going towards. One young man held the chicken near the face of another, acting as if the chicken could talk. The other person stepped back and spoke to the chicken “I don’t like you in my face chicken”. The exchange was positive with one side insisting on holding the chicken, and the other, declining. I was distracted but I think the outcome was positive. The one declining made a statement to me later about ‘never holding a chicken before”.

The following Tuesday, I realized my family had the schedule set: set up the chairs, tables, and umbrellas and use bug spray and go and greet everyone at the garden. But the other farmers also had a structure too. They would pull up in the cars and come directly to the garden and walk through the paths observing and discussing the status of the plants. We would talk about what to do next. Some would go off to check out the blackberries. If the chickens were not in the garden, some farmers would go and get the chickens. The farm has 6 swings , located all around the garden, and are often used on the way to something else. The chickens enjoyed the garden and so did the farmers. There was an ebb and flow – natural. It was very nice. New people came. We tried the kale. We discussed the varieties of tomatoes – ours were heritage breeds that grew into huge bushes.

> **6/28/11**
> Howdy Farmers,
>
> What a beautiful evening. Fluffy white clouds, a nice breeze and well, less mosquitoes (with such great company, who was counting). It is hard to believe a few short weeks ago the ground was bare when tonight the little onions were standing tall, the cucumbers were trying to climb and yes, the corn seeds sprouted! I can't believe Butter the chicken ate our beet seeds. I know, it was my own fault. I think my favorite is the mounds of dirt holding hopeful watermelon seeds. I sure hope that one hot summer evening we will be able to have home-grown watermelon!
>
> Would anyone be up for a movie on the side of the barn? On July 19 we will have the projector ready to go. It could be The General but if you have a favorite DVD, just bring it with you.
>
> What is left to plant? Oh, so much....Our potato bucket. More corn.oh, we have not done beans yet either! And not to be distracted but as I was mowing, I started to see the blackberries turning red.
>
> I almost forgot - Zeke, Romeo and Missy say THANK you. Theyare loving the extra attention and help reaching the fresh grass.
>
> Have a great holiday weekend. Hope to see you on Tuesday. 6:00 pm.
> Nite

Because of the holiday – we did move farm night to Friday:

> **7/6/11**
> Howdy Farmers!
>
> I hope you are enjoying the sunshine – our veggies have been.   We are having a farm night THIS Friday, July 8 from 6-8 pm. Why spend a summer Friday night with happy veggies, good company and ripe blackberries? YUM! Let me know if anyone needs a ride. Hope to see you soon.

That night we picked blackberries, which is not an easy task. The blackberry bushes are filled with thorns and the mosquitoes are fierce and the area around the bushes has not been mowed all season. However, none of that stopped the farmers from picking bowls of blackberries. Teams of farmers each had their special areas of high and ripe blackberries. I called everyone together and offered to spend the rest of the evening making cobbler. No one had ever had it. Everyone took home fresh eggs, blackberries, and cobbler for dessert! The email is below:

> **7/12/11**
>
> Howdy Farmers and Happy Tuesday!
>
> Last week was a bit special – we had farm night on Friday and what a night! The blackberries were lovely and so much was picked we made 2 cobblers. Now, I have not been over to that pasture since, but I am thinking that we will have more to pick tonight. Berries wait for no one.
>
> Over the weekend, Izzy and I watered and watered and weeded. Then it rained on Monday. So, everything is looking GREAT! All the plants have blossoms. We received some donated potatoes seedlings so we will try the potato barrel tonight and we have a second round of corn to plant. One mound of watermelon is up. I am worried that I did not get the others watered enough. The swiss chard is up – anyone with a recipe?
>
> Hope to see you tonight – 6:00 is perfect.

One of my favorite memories of our summer was the movie on the barn:

> **7/19/11**
> Howdy farmers,
>
> Tonight is farm night and there is so much to do including an “on the barn” movie. Harry would like the movie to be The General – a train movie with Buster Keaton. I am sure you have not seen it and it is pretty good! We will be out at the garden about 6 but we will start movie a little later (8:30 ish). Everything is growing so well. We received a bunch of potatoes to plant – so we can try the potato bucket. Basically, you put a few potatoes in a bucket with compost and as

they sprout, add more dirt and keep going… You can get a bucket-load full of potatoes! Pretty cool! See you tonight.

7/20/11
Howdy Farmers,

Wakey – wakey, eggs and bac-y. What a late night but worth it as The General saved the day. I always think there is something special about watching a movie on the barn. I loved the part when he is pulling the cannon and it aims right at him but right before it goes off, there is a little bend in the track and the cannon actually almost hits the other train and scares the other army. The General is a 1926 film and is listed as a top ten all time movie. The Wikipedia link is http://en.wikipedia.org/wiki/The_General_%281926_film%29.

But on to more important things – our first produce from the garden. I know we picked and ate plenty of blackberries but the Swiss chard is coming in. Was it Cian or Eli that said "it tastes like a leaf"? I totally agree. We will have to find some good ways to cook with it. We also have plenty of green tomatoes, a small squash, and a baby pepper too. It is really exciting to see. In June, I think it was Nolan that said we were planting "food" and I thought he was pretty optimistic – but now, it really does look that way. I will ask Harry and Izzy to help keep it watered during this super-hot week.

And finally – we have bucket potatoes planted (yeah!). Actually, the four drain tiles are a great substitute for buckets. When I see the potatoes growing up through the soil – we will add another layer of compost. I wonder how fast it will happen.

Thank you for the great evening! Hope to see you next Tuesday, 6-8.

This evening was special too because with all the "food" growing, we had some fun. It was our first night of chicken races. Sometimes the suspense of exactly what is a chicken race is better than the actual race. First I place a garden hose in a large circle (12 ft diameter or better). Then I ask people to grab a chicken and enter the "ring" of garden hose. I announce (or someone else) the chickens by name and attributes. People pick a chicken to win and then the chickens are placed in the center of the ring and their handlers' exit. The first chicken to cross the garden hose (exiting the ring) wins. There are plenty of shouts and people move around the ring trying to encourage their own chicken and dissuade others. The chickens do not appear bothered. They happily eat bugs in the ring.

We also made worm bins. Everyone, my mom included, shredded newspaper. Others used a hand drill to put holes into 3 containers. Others looked for worms. It had not been raining so worms were not so easy to find but those looking for worms did not want to stop. They checked all around the farm, quite comfortable in their surroundings. They were on their knees looking through the soil, dirty. I think we found one or two.

7/28/11
Howdy Farmers,

Believe it or not it was a beautiful night on Tuesday with a light breeze and a few clouds. The garden has really grown and we are starting to harvest. The Swiss chard is a Fordhook variety and can be used as part of a salad, or sautéed or used (what I want to try) in a pesto. The first green peppers were picked and we have some sun gold tomatoes turning – well, sun gold. Oh, and the squash. One of these nights we are going to be overtaken by the squash!

But now to the most important things – Maude (white chicken) was the clear winner of the first chicken race. Although my bets were on Carmel, Maude blazed through. Butter (brown and tan chicken that was once a buttery yellow chick) was a very close second. I think we will have to do a rematch next week!

How could I forget all that paper shredding? The worm bins were drilled, filled with newspaper and some compost, watered and we were able to find one half of one worm. Yes, it was a dry night on Tuesday. Well, folks, if you are out and about in your yard and feel so inclined to add to the worm bin, we would be very grateful. I think I will have Harry and Izzy on a worm hunt tonight.

So, you may be wondering what makes a good worm for the worm bins? The worms most often used, Eiseniafoetida (Red Wigglers), are about 4 inches long, mainly red along the body with a yellow tail. Another variety to consider are Eiseniahortensis, known as "European Night crawlers."
See you on Tuesday – we will be coming from the fair!

August was a slow month for the farm. Many of the farmers were on vacation so attendance varied week to week. Produce was in so anyone who did come took home a bunch of peppers, onions, eggplant, or tomatoes. Harry gave our first eggplant to another farmer who, in turn, made baba ganoush and brought it back to share.

For those that could make it, we began to plan a harvest party. We talked about who to invite (farmers only or the general public) and how (personal invites or a flyer) and what food we would cook and what we would do. Planning the party was exciting for everyone. It seemed like people wanted to show off all their hard work and share the garden with family. One farmer brought his camera and started to document the progress of the garden. There were discussions of a movie or projecting the pictures on the barn.

> **8/9/11**
> Howdy farmers,
>
> I know many are on vacation - lucky you! So tonight is a slow night....weed a little, pick a little and talk a little. Harry says the sun gold tomatoes and peppers are in. He also says that we can make boats and race them on creek or even safer - race the boats in the blow up pool. We also can spend some time with the goats and learning about them. Either way, hope to see soon. We will be having a big old harvest party - we just need to pick a date when we are all back in town. Thanks!

> **8/23/11**
> Howdy Farmers,
>
> Please make sure and save the date – Sept 10th to celebrate the work over the summer. I have attached a flyer – please include family, friends and anyone who would like to check us out for next season – there is so much to be proud of. From dirt to squash – the farm looks great.
>
> So tonight we will make some party plans, weed a little, run a chicken race or two and pick some produce as well. The potatoes are growing like crazy in the barrels. The corn has to be seven feet high!
>
> And for all those on vacation – HAVE FUN! And see you when you get back!

Figure 7: Harvest Party Invitation

8/23/11 – save the date flyer

You're invited to our Farm Open House
Saturday, September 10 from 6:00-8:00 pm
followed by a movie on the barn
Come and help us celebrate our second year with our farmers. We will have snacks and produce from the garden and popcorn for the movie.

This is an inclusive working farm. Farmers grow crops and in turn, share in the bounty and participate in the local food movement. This summer we grew corn, tomatoes, potatoes, Swiss chard, eggplant, peppers, squash, blackberries and watermelon. We also made worm bins and potato barrels; cooked blackberry cobbler; held chicken races; and watched movies on the barn.

Our farm night is every Tuesday. We are hoping to go year-round this year!

ease contact Lisa or Joel at 571-521-XXXX or email joel.p.wallace@gmail.com or Szymecko@msu.edu if you have any questions or are interested in participating.

Our farm is located at 3639 Noble Rd., Williamston (between Dietz and M52).
Note: The bridge is out on Noble between Williamston and Dietz.
We hope to see you on Saturday, Sept 10!

> **8/23/11 –personal letters to farm party**
>
> If it was weeding or listening, planting onions or hauling compost your contributions were so greatly appreciated! I hope you can make it to the farm open house on Sept 10. Please include your family and friends - it should be a great time enjoying our harvest! (see attachment)

The party was a hit. Farmers arrived early to cook. We made eggplant lasagna, potato chips, Swiss chard dip, squash pies, corn on the cob. Everything was from the garden. It was nice to have families see the garden and all the work the farmers did over the summer. All parts of the garden movement was represented – the plowing, the plants, gardening, and cooking. We had people in the garden, making snow cones, on the swings, on the trampoline, and seeing the animals. We did a few chicken races for fun. We ended up in the house watching a Tin Tin movie (with plenty of commentary).

> **9/14/11**
>
> Howdy farmers,
>
> Thank you. Saturday was amazing. How can such a small piece of dirt create such good times! Who knew that Maude would be out-raced by Butter? Who knew that organic potatoes, grown in a barrel, make great potato chips? Who knew that butternut squash is a GREAT pie? Who knew Tin-Tin went to the moon?
>
> So, if anyone is well rested and ready - we will be harvesting and planting this Saturday 2:00-5:00 (Sept 17). We will make more squash pies and also plant some "food" for the winter and spring - strawberries, carrots, garlic, spinach.
>
> Hope to see you Saturday. Go State! If you wear green you don't have to compost! (I will not send this to Joel!!! haha)

We did plant some cold tolerant plants like spinach and plants that would come up before the blackberries such as garlic and strawberries. As it got colder, we tried to protect plants with a plastic cover but strong winds followed by a strong frost really damaged the cool season vegetables. Tuesdays also became a difficult night with schedules and school the next day. We put the garden on hold until after the holidays but the interest did not wane. We met over some new chicks and thought about the year. I asked the questions (L)

> (L) What do you guys remember about last year?
>
> The chicken races; squash and the…well, I was thinking this year we could grow pumpkins.
>
> (L) What do we want to do this year?
>
> I liked that we could each plant a plant for ourselves. And how we got the plants. We didn’t pick them up from a huge PLANTMART.

> We went to the neighbor's, down the street. It was local. That was nice. Because they're locally grown. And they're extras from them. From people who didn't pick up their orders.
>
> (L) So, what else do you remember? You remember the chicken races; you remember the squash. What else do you remember?
>
> I remember the watermelons. And I bought this 200 pound watermelon grower. It grows 4 200 pound watermelons. They're like giant watermelons. Last year, watermelons were 'miniscule'.
>
> (L) What did we do last year that we don't want to do this year?
>
> The plastic over the strawberries didn't work.
>
> (L) What do we want to do this year?
>
> Work on the trees; more tree-growing. We should grow pumpkins. Have a special portion of the garden for chicks. Avocadoes, pineapples,
>
> (L)What was your favorite thing from last year?
>
> Roasted seeds; snow cone maker.
>
> (L) What are the different activities we did?
>
> The party! We should have a harvest party. A lot of people came. They could get a taste of what they can do. We could have 10 parties. Or a party-a-week.
>
> (L) What about cooking?
>
> Yeah! Making eggplant lasagna. I made potato chips
>
> (L) What about the blackberries?
>
> Oh, I have a secret stash.
> There is a big discussion on where the "stash" is, and everyone leaves. Harry returns with a map he and another farmer drew of the farm. I promised not to show it, because it has their secret blackberry stash.

This is how the journey to the social farm ends, with everyone in the garden, getting ready for this summer.

CHAPTER 5

ANALYSIS

Autoethnographers must not only use their methodological tools and research literature to analyze experience, but also must consider ways others may experience similar epiphanies; they must use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders. To accomplish this might require comparing and contrasting personal experience against existing research (Ellis, 2010).

The journey to the farm and the observations at the farm bring together different themes of network building, voice and choice, integrated therapy, and gender. Although the setting is a farm, the analysis is much broader. This analysis is not to promote farming for those with ASD but to provide insight into opportunities that can foster positive outcomes. Both ethics and economics are discussed as well as future opportunities, in the idea that for care farms to be successful, they have to be sustainable by embracing human rights over the environment and profits.

Paradigm Shift

From travelling down my journey to the farm it is clear that what is needed is not another service provider, but a paradigm shift. Comparing our experiences over our entire journey to the last year with the social farm brought up very poignant differences, differences in the approach, respect, and rights for those with ASD. The current model for those with ASD and society is a patient/practitioner model or a client/server framework. From there we see that this client/server framework is reminiscent of the expert model (we tell you what to do) that I was most familiar with in the environmental sciences. I propose a shift away from this model to a non-expert based, open, person-centered approach.

The examples below were documented “in the moment” with emails and reflections. It was only in the summation, the accumulation, of these events in contrast to the social farm, that the need for a paradigm shift became apparent.

Regional Example

Harry attended community music school:

> The new building and new activity meant that it would take time (and a couple of sessions) until I got Harry into the classroom. However, once we were there, he LOVED IT. The therapist was amazing. She engaged Harry in the instruments. He would play the drums and she the piano and they would sing, often about pirates. They played loud and Harry seemed to play with his soul.

A cellist instructor disrupts the session:

> at a session, a man (cello instructor) came in the door yelling at Harry to stop, and saying that Harry was interrupting his cello session, and he could not teach under these circumstances. The look on Harry’s face was one of utter astonishment – a wide-eyed deer look. I, too, was taken aback at someone yelling at my son during a therapy session. The therapist was flushed as well.

There was a sign on the door. The cello instructor was condescending:

> In a later explanation to me, the cello instructor explained that I needed to understand that "from where he was sitting ... the sounds coming from the room seemed like noise ...", but when he realized what was "going on" in the class, he "understood" and "had no problem" with the sounds. While responding to my strong assertion that the interruption and his actions in front of the student were inappropriate, he expressed empathy for what my family was "going through"

Letters to the schools produced no action by the director.

> As parents electing to participate with our child in the music therapy program at the CMS, we assume that the School, as a whole, is receptive to all students and supportive of their efforts. We would also assume that addressing issues which are not our own would not subject us to comments which are patronizing and condescending.

After weeks - an apology was finally given by the associate:

> First of all, I deeply apologize for that incident!! I will take the blame because I do lots of PR and talking about music therapy and what we do, but never to my co-workers at CMS!!

And she explains the cellist actions:

> I think TOO many people are not yet able to see all people as people first!!

She also attaches a poem. For us:

> We never heard from the director. No one from the Music School apologized to the individual that they harmed – Harry. Instead they want me to understand that people may not view him as a person – and it is even written in the poem. They did not create a safe and nurturing environmental for Harry. And, they, themselves, did not feel Harry was person enough for an apology. Fuck the poem. We never went back. Life is too short to put up with therapy that is not participant-centered.

This incident is at a recognized regional therapy program at a leading university. It is actively marketed to families with kids with special needs. The music school holds themselves out as a group that is sensitive and knowledgeable for the population it serves. As parents we paid for these services and they were not cheap. We drove to the sessions weekly. Although the therapist was amazing, she yielded to the other teacher. She did not stick up for Harry. The cellist wielded power, not because of numbers IN the program, but a systemic acquiescing to the "norm". Both the teachers were part of the MSU community music program. However, by their actions both agree that the therapy music lessons are less than conventional music lessons. The participants in the therapy program deserve less. They deserve to have their music and their voice quieted in support of others.

Leadership in the school confirmed this unequal relationship when they did not treat Harry as a person. Teachers and leadership at the school treated him and us with pity and patronization. The program is not a safe environment. Hanging signs alone does not mean support and advocacy. The school continues to promote this tainted view of inclusion and propagate it through their status.

Local Example

At an even more local level, the school system proved uneducated or uninformed:

> First grade was turbulent for all of us. Harry's teacher was not receptive of me being in the classroom. She did not want a partnership between parents and the school, at least one defined by me. These are the statements she made to me (which I captured and used in a presentation that spring).
>
> "Boys will be boys" when another boy was rough-housing with Harry at recess.
>
> "He looks normal. Do we really want to call him out?" when I asked about setting aside some time to talk about autism in class
>
> "I don't understand why he was over there anyway. He doesn't like kickball." when Harry was pulled down by his coat by another child while she was in charge of watching the class on the playground.
>
> "He doesn't look at it" when I asked why the visual schedule was not up in his class.
>
> "Sometimes I like to work alone too." when I questioned why Harry's desk was separate from everyone else's.
>
> After 3 months of conflict with his teacher, I met with Dr. S and he dictated pages of solutions, which I sent to school. Then, I called a meeting with the school to amend the IEP with a copy of his recommendations and I brought a coffee cake. Every item that Dr. S recommended was implemented. The visit with Dr. S was $150. The coffee cake was zucchini chocolate. The change in his classroom – priceless.

These scenarios, although quite troubling, demonstrated that outside, third-party assistance is needed for a positive change. At the Individualized Education Planning (IEP) meeting, the staff resources assigned to Harry were: an in-class assistant; an occupational therapist; a social worker; a speech and language therapist; an autism consultant; a school psychologist; and his teacher. All are aware of and have been trained at various levels in child development. They are knowledgeable about what students need for success and have worked with hundreds of students, many with special needs. Yet every support Harry received felt like a fight against us, as parents. Should I have to have Dr. S write a letter to have visual supports in the classroom for my son who is autistic? Every one of Harry's resources knew that visuals schedules were useful for those with ASD, and in fact, the school has laminated schedules with Velcro, already made for that reason. Should I have to go to Dr. S to have Harry's desk placed, not just in the classroom, but as part of the class? Every one of Harry's resources knew that physical inclusion does not constitute real inclusion, yet they accepted it because the teacher found it easier as a long term solution than integration. Teachers have a lot of power in their classroom daily activities. If they choose to isolate a student, change may not happen without parental oversight and outside assistance. The principal did not set a tone at the school to support all students, or the teacher would not have felt empowered defending her actions in her classroom. Other resources did not advocate for Harry. It represents a systemic failure that a parent has to fight the experts and is powerless, in a system filled with knowledge and whose purpose is to educate.

Program Delivered State-wide Example

Then there is the role of programs, delivered state-wide and sponsored in the schools, such as the Peer-to-peer program:

> "Peer-to-Peer Support Program that involves students with social needs and students nominated by their teachers as positive role models" (one student with ASD paired with one without ASD). The student with ASD is the receiver –the "target" for assistance. The student without ASD is the mentor – the provider of assistance. Harry would not have the opportunity to co-mentor. There is training offered for the "nominated" students, and not the "target" students: (email from AI consultant)
>
> > 1. Psychologist: Provides students with an overview of disabilities and how the disabilities impact socialization
> >
> > 2. Social worker: Provides students with an overview of how behavior is impacted by disabilities
> >
> > 3. Speech/language therapist: Provides students with an overview of speech & language skills (pragmatics, fluency, reciprocal conversations) and how disabilities may impact these areas

> 4. All adults involved will provide training to students regarding strategies/tools/ideas to assist students with social needs
>
> 5. Question and answer time
>
> 6. Program expectations (on-going)
>
> Nominated students will receive training one time per month. The two peer groups will participate in a social luncheon/recess activity one time per month.

This is a program distributed throughout the state, which was developed by experts in the field, to assist those with special needs. As we stated in a letter, there was no mention of review with those “targeted” students for their opinion or their perception of the program or of their peer counselor, nor of determining their interest in participating in the first place. Harry was selected and we were notified (almost as an honor) that Harry was one of the “targeted” group. We declined. In a letter we stated:

> I welcome education for anyone about how to better interact and consider people on the spectrum, including the students nominated to serve as positive role models. An essential component of that instruction must be learning to recognize that every student has opinions and perspectives that are credible and have value and should be considered. In short, ask students questions and listen to their answers. I think that is lacking in this program, with respect to the students on the spectrum. It's a disservice to students on both sides of the program to structure this as something performed by the 'nominated students', and performed on the 'students with social needs'. We can't be part of that. If there is program where all students are peers and the exchanges happen in both directions, we would be eager to participate. Please correct me where I'm mistaken. I appreciate the value of social skills education, and will continue to look for a model that gives kids on the spectrum appropriate consideration.

The autism consultant’s reply:

> In regards to your concerns regarding the Peer-to-Peer Support Program, you are welcome to attend the Peer-to-Peer Support Training to learn more about the program's components.

Again, we see those specifically trained and educated not only in child development but in autism quash the voices of those they are supposed to support. They also propagate this injustice by teaching others that those with special needs deserve to have their voice quashed. Co-learning was not even an option. It is as if those with special needs should be thankful for being subjected to this “opportunity”. The demarcation between atypical and special needs students highlights differences and not strengths. This creates an unequal power structure for students with one group excluded in structure of the program. Mentor students receive training. Mentor students receive recognition and are awarded for their participation. Targeted students are in a position of receivership without a voice, or awards, or training. Harry, himself, was not even asked if he would like to participate. The question was only posed to his parents and that it was not really a question of substance but of eligibility. As parents, we were supposed to embrace what was offered as services, state sanctioned services, for our son. When we questioned the services, we were directed to training so that we would be more informed about the benefits to our child.

On a local, regional and state-wide level, parents and those with ASD are regarded as uninformed or uneducated. For the music school and peer-to-peer program, we were powerless to change the services offered so we choose to “opt-out”. In the school setting, which is more compulsory, we relied on a third party who was a well recognized and accepted expert to impose change. Harry’s voice was never acknowledged. Our voice as parents was not heard.

In my preface, I mention the need for the community to know our children. However, it was not the general community that I am most appalled by; it is those service providers that studied child development, educators, and those in the “system” that hold themselves out by their positions as experts. I knew I would be an advocate for Harry, but I never could have imagined who I would have to be against.

Social Farm Examples

I thought social farms may be a place to provide inclusion, especially compared to school systems, but I realized other social farms are not immune to speaking from a similar position of power to those with ASD. Literature on care farms networks focuses on a variety of regional and national professional networks that tend to define stakeholders as “farmers, agricultural and health organizations, financiers, political organizations, and scientists.” (DiIacovo 2009) Also discussed are partnerships which represent health providers and the county as “partners in recovery”. The separation of client, or service user, to provider and practitioner is consistent and the former is not included in the discussion of networks.

Therefore, care farms are not the answer in and of themselves, what is needed is to listen to the voices of those with ASD:

> Special education teachers often put too much emphasis on deficits and not enough on building on areas of strengths. (Temple Grandin)
>
> ..unrealistic and divisive notion in our community that becoming normal is the only and optimal goal…” Jerry Newport (with Aspergers) in Sicile-Kira (2004)
>
> Tell the parents that they [with autism] may look at things differently and look *with* them. (Harry Szymecko)

Inclusion Examples at our Social Farm

I believe the farm was a model for inclusion because we set a positive tone and used consensus or facilitated decision making. The outcomes of this setting included a long term engagement with interests of expanding.

Tone

The social farm was structured to be inclusive, as an UFO, or universal farming opportunity, it was open to all abilities. I felt that I knew more about autism, so working to include that population was important to me. I also knew how much Harry enjoyed the farm. Calling the farm inclusive is different than making it inclusive. Setting the right tone and supporting that with actions was important.

People were invited to participate. They were asked based on past relationships. The tone was meant to be welcoming.

> With the ground plowed into lumps of grass, it was time to open the doors for the summer. I did not go with the flyer. I was going to work with a small group of forgiving families and grow by word of mouth.

Emails also tried to convey my thoughts on the farm being inclusive.

> I am an advocate of social farming – the idea that people benefit from more than just the good food grown on a farm. I have an area plowed and have a couple of folks that – as we work together and plant – will share in whatever comes up and maybe have a good time doing it! We are going to get started tomorrow (Tuesday) about 5:30,. This is informal and people can engage in as much (or as little) as they want. We have the chickens too – and will probably get some more (oh, we use the eggs). Let me know if he needs a ride - we live close (3639 Noble).

As people came to the farm, I wanted them to feel welcome and set a positive tone for the evening.

> I wanted to make sure and greet them. I spoke with the kids about welcoming each person.

And when I found myself beginning to feel tired or wanting things to happen faster, I just had to remind myself :

> It was a slow process, but with social farming, you have to know that efficiency is not the goal, at least that was what I kept telling myself.

Part of setting a positive tone was also removing any perceived constraints for participation. All farmers were included in every process – there we no assumptions.

> So, Joel took one young man over to Gene's house (in the van) to pick up transplants that he had started.
> Two young men, using a wheelbarrow and shovel went to the compost pile – chatting. One young man and I were placing newspapers down when the wind blew. All of us went running to catch the papers.

Acknowledging each other and the work we did also put a positive spin on some tough times. This was done in weekly emails:

> If it was weeding or listening, planting onions or hauling compost your contributions were so greatly appreciated! I hope you can make it to the farm open house on Sept 10. Please include your family and friends - it should be a great time enjoying our harvest!

To be respectful of time and also show our commitment, I pushed for the same night every week:

> I wanted the farm to have a consistent night, no matter what. I wanted that for our family schedule and to show our commitment, as well as for the structure that provided, especially to those with ASD.

Decision-Making

As an UFO, or universal farming opportunity, it was open to all abilities, so individuals had to choose activities and levels of engagement. Those who showed up on farm nights could set the agenda and their level of interest. Those that choose not to attend were not punished, but missed. Whatever was grown was divided. This was harder in the beginning when delayed gratification seemed like a long way off. Many of the people that came to the farm, had actually farmed. But then, production was not the only reason to participate.

I used email to make suggestions so that farmers could ponder or families could use to help with preparation for the farm night.

> Speaking of next week – I would like to put the chickens in the garden next week. Many of you have not met all of our hens. I think it will be fun!

> Would anyone be up for a movie on the side of the barn? On July 19 we will have the projector ready to go. It could be The General but if you have a favorite DVD, just bring it with you.
>
> The swiss chard is up – anyone with a recipe?

At the garden, I tried to facilitate discussion or decisions. This was needed more at the start of the farm.

> I asked if anyone would like to drive the lawn tractor (blades not spinning) with a rake attachment. Everyone wanted to drive.
>
> I asked what they wanted to plant. One said “food”. I think he was very optimistic. We made a list.
>
> Standing in the garden with a table with the plants and seeds on it, I would ask where the peppers should go and someone would say “right here” and all of us would think about it and give an opinion. I would say “who would like to plant it?”
>
> We began to plan a harvest party. We talked about who to invite (farmers only or the general public) and how (personal invites or a flyer) and what food we would cook and what we would do. Planning the party was exciting for everyone

Over time, farmers began to realize choices and began to self-select.

> When I looked up, one young man was petting a horse. I couldn’t blame him.
>
> As I looked around, one young man was sitting in a chair with Harry’s book.
>
> I would have them look at the table and pick out what they would like. All the plants and seeds had a photo of a grown plant. If someone wanted to plant something specific, they could show where they would like to plant it.
>
> If the chickens were not in the garden, some farmers would go and get the chickens.
>
> The farm has 6 swings, located all around the garden, and are often used on the way to something else
>
> We also made worm bins. Everyone, my mom included, shredded newspaper. Others used a hand drill to put holes into 3 containers. Others looked for worms. It had not been raining so worms were not so easy to find but those looking for worms did not want to stop.

The farm supported the principle that everyone has a right to choose:

> When I went to pick up N yesterday, he didn't want to garden so he wrote a note saying "I quit. N". That is a great reminder that Tuesdays are meant as an open farm day and that you can come or "quit" for any day. Of course we miss you but there is always the next week. That is one thing about farming – there is always plenty to do.

Outcomes

The social farm operated every Tuesday night. People participated every week but not all the same people every week. Excluding my family, there were approximately 20 participants (see network discussion for descriptions). There were some outcomes that were not surprising such as the impact of animals but other outcomes were amazing such as the farmers wanting more parties and more engagement of others. The farm was full of movement and plenty of mosquitoes, yet sensory issues were not prominent:

> I still was not sure that was going to work because of the noise but each young man wanted to drive it. They took turns, they wore headsets and the drove it back and forth in a variety of gears.
>
> It was starting to get a little dark but the worst thing was the mosquitoes. They were out with a vengeance. The wind had stopped. We sprayed each other with insect repellant but it didn't seem like it helped at all.
>
> If the chickens were not in the garden, some farmers would go and get the chickens.
>
> That night we picked blackberries, which is not an easy task. The blackberry bushes are filled with thorns and the mosquitoes are fierce and the area around the bushes has not been mowed all season. However, none of that stopped the farmers from picking bowls of blackberries.
>
> It had not been raining so worms were not so easy to find but those looking for worms did not want to stop. They checked all around the farm, quite comfortable in their surroundings. They were on their knees looking through the soil, dirty. I think we found one or two.

The farm was a great place to practice social skills in the natural environment:

> One young man held the chicken near the face of another, acting as if the chicken could talk. The other person stepped back and spoke to the chicken "I don't like you in my face

> chicken”. The exchange was positive with one side insisting on holding the chicken, and the other, declining.

However, it was not the plants but the animals that were the draw and farmers engaged with them at their own pace and in their own ways.

> When I looked up, one young man was petting a horse. I couldn’t blame him.
>
> Harry and Izzy and others would show each other how to pick them up. Then the chickens were carefully carried to the garden with giggles and flapping and happy sounds by kids and birds.
>
> If the chickens were not in the garden, some farmers would go and get the chickens.

I recognized this special relation with the animals in my weekly email:

> I almost forgot - Zeke, Romeo and Missy say THANK you. They are loving the extra attention and help reaching the fresh grass.

Farmers became vested in the farming process. They owned it and were proud of their work and the results:

> Farmers wanted to identify their own plant –“I planted this one” or the section.
>
> People pulled their cars around the birch tree loop and came right out to see how things were growing.
>
> When people came, there were smiles and walks around the garden on the horse-feed-bag paths. We were all getting to know each other.
>
> There was a lot of fuss by the farmers at which section the birds should be in and whose plants they were going towards.
>
> Teams of farmers each had their special areas of high and ripe blackberries.
>
> Harry gave our first eggplant to another farmer who, in turn, made baba ganoush and brought it back to share.
>
> It seemed like people wanted to show off all their hard work and share the garden with family. One farmer brought his camera and started to document the progress of the garden. There were discussions of a movie or projecting the pictures on the barn.
>
> Farmers arrived early to cook.

> We had people in the garden, making snow cones, on the swings, on the trampoline, and seeing the animals. We did a few chicken races for fun.
>
> We put the garden on hold until after the holidays but the interest did not wane. We met over some new chicks.
>
> I liked that we could each plant a plant for ourselves. And how we got the plants.
>
> We didn't pick them up from a huge PLANTMART.
>
> We went to the neighbor's, down the street. It was local. That was nice. Because they're locally grown. And they're extras from them. From people who didn't pick up their orders.

Farmers developed relationships with each other. They invited others to come to the farm. At our first meeting of the farm this year (2012), farmers expressed their interest in expanding.

> We should have a harvest party. A lot of people came. They could get a taste of what they can do. We could have 10 parties. Or a party-a-week.

They wanted to expand what we grew to include pumpkins. One had already bought seeds for bigger watermelons this year.

> Work on the trees; more tree-growing. We should grow pumpkins. Have a special portion of the garden for chicks. Avocadoes, pineapples,
>
> I remember the watermelons. And I bought this 200 pound watermelon grower. It grows 4 200 pound watermelons. They're like giant watermelons. Last year, watermelons were 'miniscule'.

One of the best outcomes, is that the farm is going to continue this year (2012).

> When I asked about the blackberries, there was a big discussion on where the "stash" is, and everyone leaves. Harry returns with a map he and another farmer drew of the farm. I promised not to show it, because it has their secret blackberry stash. This is how the journey to the social farm ends, with everyone in the garden, getting ready for this summer.

Discussion and Comparison of Different Paradigms

Originally, we moved to the farm to integrate Harry's therapy and love of animals into his daily life. As the social farm developed, it was clear that we were not just trying to replace services; it was an outlet that provided equal access and decision making to all farmers, those with and without ASD. Sure, the farm has built an environment that can help address some ASD symptoms so that it is easier for those with ASD to become an active participant in all aspects. However, this alone is not the shift. The paradigm shift is that others, without ASD, change their perspective to accept the diverse abilities of others and to listen. To move from an "expert" whether that is a therapist or a parent, to a partner. If the farm helps get those with ASD to the table, the other contingent has be willing and able to sit on yoga balls at the same table.

The table below is a comparison for the current frame with the frame developed on the farm. As in the community music school example (regional example), people with special needs can be subjugated to the norm, whereas the farm did not make distinctions between farmers, based on any label. Farmers participated at their own abilities. As in the peer-to-peer (state-wide) example, experts pushed a uni-directional education onto parents and families in order for them to understand the program. Participants that were identified as the "target" group were not included in trainings, discussions or choice. The farm embraces co-learning and flexibility. The farm respects voice. There was uneven power distribution between experts and families or individuals with ASD. The farm, by fostering a positive tone and facilitation or consensus decision-making reduced the uneven power dynamics. We had our meetings in the garden, with the chickens, and on the go. Topics were discussed over time and options were open. The goal was not efficiency but dialogue. All of us had to maneuver to meet together. There had to be a release of power, certainly on my own part. And there had to be trust on everyone's part. It is not easy to make a paradigm shift. Starting at the farm and moving outward is a grassroots approach but one that can resonate widely.

Table 6: Comparison of Paradigms

Current Frame	Our Farm Frame
Special needs subjugated to the norm (CMS)	No distinction between abilities. Everyone is a farmer
Expert push education for compliance (P2P)	Co-learning
No input to decision making (P2P)	Facilitated or consensus decision making
Lack of power (school)	More equal power distribution

Perhaps through the social farm experience, there is conscientization. Conscientization serves as one of the central ideas in Freire's conceptualization of education as a form of liberation. In “Pedagogy of the Oppressed”, Freire refers to learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality. (Freire, 1973) Conscientization is connected with his notion of authentic praxis – which is an approach to learning that involves a combination of action and reflection. It is through critical reflection and dialogue that the oppressed are liberated. (Foster-Fishman, 2007) This approach criticizes the traditional ways of knowing. Similar to the experiences at the farm, if people learn to have a voice in a society that is oppressive, that treats them as those that have special needs but not equal rights, then they will push for change. This could be the paradigm shift.

Voice and Choice

“If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse human gift will find a fitting place”. Margaret Mead

Recognizing differences; supporting differences; and the inclusion of differences is our path on the farm, with a belief that such a setting promotes inclusion. Active inclusion requires voice. The farm setting provided the opportunity for voice through decision-making, choices, and discussions. Vehmas showed that the more accepting environment that the individuals with intellectual disabilities are surrounded by, the more chances they have for collective self-empowerment and 'expanded identity' and, consequently, the more chances they have for exhibiting their agency and moral responsibility (2011). Inclusion of those with disabilities, has intrinsic value, that is, the democratic right to speak up in a process that ultimately aims at influencing their lives and serving their needs (Caron-Flinterman, 2005; Abma, 2006; Greene, 2006). Diverse team structures are desirable in terms of bringing experiential knowledge, establishing trust, gaining access and entrée, translating jargon, revealing prejudices and developing new perspectives (Nierse, 2011). This is very similar to the farm where trust building and knowledge sharing brought new perspectives. Farmers were used to talking to each other and, as a result there was an atmosphere of openness and inclusiveness. Farmers felt comfortable being more critical and assertive and not just accepting everything because I said it, or someone with ASD said it, or another adult said it. Voice also had timing. Sometimes we just agreed to keep moving and agreed to address some question or issue later. There are many choices on a farm, and only a few are time dependent. This also helped build trust and enhanced mutual understanding (Karpowitz et al., 2009).

Voice and choice became a guide for the farm process, trying to be especially respectful of those with ASD because they may not have been given the opportunity for voice. While historically it has been believed that individuals with ASDs were unable to reflect on or to report reliably on their own affective states, Sheldrick found evidence that high-functioning adolescents with ASDs are able to report on their own quality of life in a valid and reliable manner (2012). Adolescents with ASDs are aware of and can accurately report on the deficits associated with their ASD, especially in the realms of social and emotional functioning. (Sheldrick, 2012)

For the farmers on our farm, we knew both of those facts to be true, but that opinion is not universally held. That is why it was a teachable moment when Harry read his speech to the School Board, or when we declined the school system's peer-to-peer services. Schneider, in her book "Sensory Secrets", states that "people with special needs can be our finest teachers." But society has to allow them to have a voice.

Social integration, rather than physical integration alone, is a necessary component of educational programming for students with disabilities. McLane, Meyers, and Pruzek (1998) found that the general education classroom does not systematically encourage peer interactions for students with mild disabilities. In addition, they concluded that teaching activities designed to foster peer interaction are seldom used and, when used, are generally not appropriately matched to student needs. The farm provided both physical and social integration. Friendships were formed. The farm, as an outlet for open communication, could provide insight about ASD to each other perhaps reducing "socially created disabilities" (Higgins, 1992). Through sharing, farmers could gain information about the nature of ASD and coping strategies (Denhart 2008). This is a three-way street of recognizing differences; supporting differences; and inclusion.

Recently, a small group of last year's farmers discussed plans for this year. The consensus was to have more parties: a sow party, a grow party, and a harvest party. There was strong interest in inviting others to include in farming; to show it off; and to entice them into farming. There was a strong interest to include the movies on the barn so that they can watch movies with friends. Chicken races were a favorite and future races should include the new chicks. Overall, their idea was a repeat of last year but expanded by people and plants and ideas such as pumpkins; a tree farm; and flowers. One farmer mentioned that we still need to get our seeds and transplants locally (from fellow farmers), until we can do them ourselves. When I mentioned cooking, everyone agreed that they liked to cook. When I mentioned blackberries, all the farmers left the discussion in pursuit of their favorite (secret stash area) of blackberries (just to check). To me, that is voice and choice.

Developing a voice was a process beginning with supporting Harry in an integrative classroom, being comfortable about the "label" of autism, being open and honest with him and his diagnosis, and giving him the opportunity to speak for himself and coaching him how to do it. Harry's voice has been easily blocked: when, at Harry's IEP I elected to send him to class instead of helping continue to participate, I blocked his voice; when Harry's teacher did not want him to discuss his ASD in class, she blocked his voice; and when Harry was not prepared for a meeting, he was not able to actively contribute.

One time I was going to guest lecture in a class, I asked Harry what should families know when they have a child with autism.   Below are my slides. They capture Harry's discussion:

> Harry Szymecko (age 10)
> Presented by: Lisa Szymecko (mom – age not specified)
> January 26, 2011
>
> These answers are Harry's, as he sat in the back seat, kicking like crazy on the seat in front (mine). I tried to capture his actual words.
>
> Mom: "Harry- I am going to go to E's class on Wednesday"
>
> Harry: "Her cooking class?"
>
> Mom: "No, a class with students 19-20 years old, like Matt. What should I tell them, you know, what should they learn about families with children with autism? What would you want them to know?"
>
> Harry was quiet
>
> Mom: "Harry, that is ok if you don't have anything…"

Harry: “No, mom. I am just thinking”

1. Do it their way

    Mom, I think you told me about this where there was a person was getting dressed and they were severely handicapped and the mom was getting frustrated but then she looked at where her daughter was looking and her daughter was looking at a falling leaf. The mother said “Now, I get it. We will do it your way”
    (recall of passage in Eva Kittay)

2. Those with autism may have a different way of looking at things

    Z found it first. She saw the hidden picture first

3. Different people have different needs

    Even a typical person, I don’t want to say normal- but they may want something bumpy or need something to help them learn, or for everyday life, disabled or not. For some people who like to rock, they have this seat that you can rock in, they have something.

4. Tell the parents that they [with autism] may look at things differently and look *with* them

    Like math. You guys get so frustrated when I don’t know how to do something.
    Mom: “what should we do?”
    See what I am having the most trouble with. Finding what needs the most help.

5. Be gentle

    Be kind ‘cause sometimes a different tone will set the scene for them. Someone is angry or someone’s upset. Because that helps a lot.

6. Educate everybody about it

    Because I think the more people should know in a family or class because once they are introduced then not everyone will push them off. You know, not being very nice and can be pretty much a bully because they know that they won’t fight back. It will help, even if the other person is nice to them.

7. Don’t underestimate them

    You know like D. You were just talking to him and he has a little bit of trouble but you were just talking to him and he has a perfect brain.

Harry’s 7 things:

    Do it their way
    They may have a different way of looking at things

Different people have different needs
look *with* them
Be gentle
Educate everybody about it
Don't underestimate them

Harry is right to point out that inclusion is a two-way street. He didn't feel the need to tell people that he benefits from therapy, but to tell them to give him (and others) the most basic right of opportunity. Harry has to be in a good place to actively participate in his life. His symptoms have to be reduced or Harry has to be able to hear over them. He has to know what to expect and when so he can prepare. He has to learn to prepare for the unexpected. But even that does not mean he can participate. People can block him or work against him. As much as he has to know the language, others have to know his. Disabilities or exceptional abilities have to be viewed, not as intentional, but as part of who he is.

Inclusion is more than physical space. It is more than Harry learning to conform. There is a bigger duty for society to "get it", and give him his rightful place where he can live his life within the culture of a community, a caring culture. This is why it is a human rights issue.

Harry can actively participate in therapy but when institutions fail, individuals can still make the difference. It was surprising that one constant on my journey was the proactive and caring bus drivers, regardless of the school district. A bus driver held my hand at the kindergarten round-up; another came to our new house to meet Harry; and another protected him from bullies on the bus. When our regular bus driver was replaced, the bullying resumed. Knowing my push for Harry to speak up, he went to the assistant principal's office that morning to voice his complaint. The individuals involved were to lose bus riding privileges starting the next day, but they were allowed to ride the bus home. They and their parents were informed. On the bus ride home, Harry was confronted by the students to be penalized. He did not lie when asked if he told what was happening on the bus. It was a tough ride home. Now, the bus has video cameras installed.

Although there were yearly issues with the IEP, the years where there was a partnership between the teacher and the parent were the most successful, regardless of the overall amount of conflict. Teachers and the AI consultant, using their own time, built an opportunity to share with each other, with me, and with Harry. Harry’s looping classroom (two years in a row with the same teacher) was probably the most successful because of her willingness to partner and her growth in knowledge about Harry, in addition to Harry benefiting from the overall positive structure. For many years the AI consultant led a very successful social skills group. When the AI consultant was replaced, the replacement did not see any value in the group and we lost that opportunity at the school, but were able to pick it up at the farm. When the school system was difficult to deal with, and individuals involved were unresponsive, it was necessary to bring in outside resources, such as Dr. S. Money available to a family to spend on private resources can make a difference and overcome some of the most challenging barriers in dealing with the school system.

Farm Results, Intuition, and Literature

Insight from the farm (summer 2011) showed that the farmers (including me and my family) were vested in the process. We participated every Tuesday. We all wanted to show off our work to others, to extended family, and bring others to the farm. My siblings came to the harvest party. One farmer brought out-of-town guests to our movie night. Other farmers wanted to take home plants to grow at home. We all wanted to cook the food that we grew. Preparing for the harvest party, farmers wanted to make potato chips, pizza and corn muffins: all readily identifiable food. My favorite was the blackberry cobbler.

Relationships developed regardless of diagnosis or abilities. We learned from each other and about each other. This was very apparent to me when I was picking up a few farmers and said, reluctantly, that a certain other farmer would not be attending. I was sure that one of the farmers I was driving was going to opt-out for the evening. To my surprise, that was not the case! New relationships had developed. I also noticed that my weekly emails were evolving to become more personal, with more questions and humor. Ride sharing became more common as we learned about each other and how to meet each other's needs.

It is also true that contemplating the journey, and particularly the farm, helped me develop my voice, and through facilitated decision making, my voice and other farmers became a collective. We worked for inclusion, together. The farm also offered freedom of choice. As we decided what we would like to do, farmers could work at their own pace and abilities. I liked to plant but like most farmers, not as interested in weeding. It was nice when the produce started to come in because I love to cook and when I offered, many people joined me inside. Sometimes I would have a favorite recipe, other times we would look on the internet.

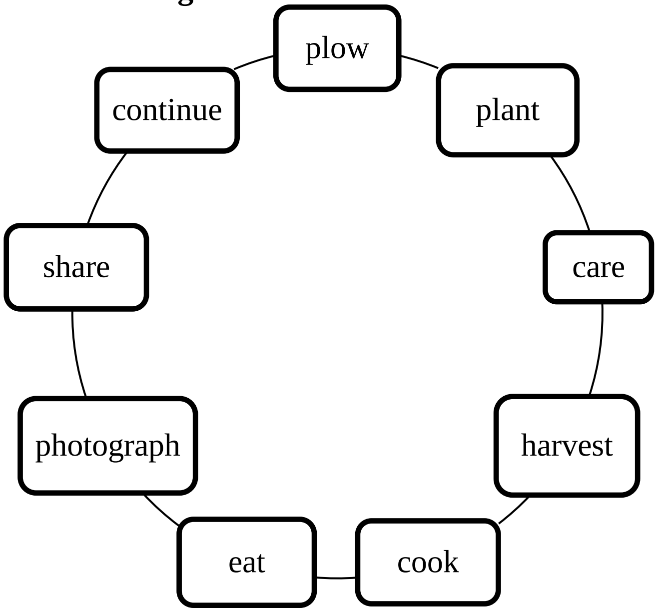
Many Tuesday nights my mom was outside with the rest of the farmers. She would say that she wished she could get down and weed. So, I offered to help her (with Joel). She said, 'I don't want to do that!" I laughed. No one really likes to weed when there is a choice!

When we ended in October, it was scheduling on my own part that caused a brief hiatus of the Tuesday farm nights. However we just held a meeting to discuss this summer (2012). There was a lot of excitement and ideas. One of my favorites is that the farm is going to continue.

Therapies

Although therapeutic values were not measured on our social farm, there are many opportunities to engage is a variety of activities that are therapeutic. In this process of farming, there is dialogue, conflict, ideas sharing (social skills); planting, hauling compost, digging, swinging on swings (OT); understanding of people and situations (speech); all in a natural environment. The figure below shows our cycle of farming with success measured by the interest in sharing across networks and the desire to continue.

Figure 8: Cycle of Farming



Particularly, when I consider my son, I believe the farm incorporated therapy into his life. The farm gives him heavy, manual work to do. I also note that those that came to the farm did not sit – unless it was sitting on a swing or crouching in the weeds, or in-between a fence climb. Hauling compost, carrying water, giving hay are all gross motor activities. Planting, weeding, and writing about the farm are all developing fine motor skills. Although the farm is full of smells, mosquitoes, dirt, and animals, Harry was not hampered by sensory processing. In fact, the lack of sensory issues for farmers outside on the farm was startling. People tasted kale ("it tastes like a leaf") or handled worms and chickens without issue, and yet would wash and rewash hands during our cooking time, careful not to get anything on them. Perhaps with swings, and animals and the farm, there were plenty of clear choices and farmers could pick and choose activities depending on their interest and their need. According to Kay, the "inability of the autistic to make choices, especially when their experience is limited, needs no documentation". By enriching their experience through many activities repeated often enough to be internalized, the autistic residents gradually become able to make choices that begin to reflect each person's developing personality".(1990) Although I disagree with the language, which was more common in 1990, the idea that those on the farm, knowing and learning the options on a farm, can help with self-regulation. It is not uncommon to see someone planting or working in the garden with a group, then off to pet a horse, or swing on a swing then return to the group. The farm provided opportunities to cope by either imitating norms of behavior or making sense of the world within their unique perceptual systems (Nikopoulos & Keenan, 2004).

Working in a diverse group also built social skills in a natural environment as opposed to a therapy room or small classroom setting. For indoor settings, social skill development uses visuals, games, and role playing to discuss and learn societal acceptable responses in social situations. (Coucouvanis, 2005). The farm provided one-on-one, small group and large group opportunities. Games like the chicken races allowed the farmers to discuss rules and behavior. Dialogue and sharing was positive. Because farm work is diverse and challenging, each person can see strengths in each other. It reduces the overall power structure. Most of the farmers have spilled a load of compost. Some of the farmers are not excited about holding chickens. All farmers have ideas and interests. We used consensus building for decision making. We did not try to make decisions too quickly so that farmers can ponder – we may discuss issues and ideas one week and wait to decide the following week. We may say “think about this at home”. We use visuals. We give time to talk in small groups and then bring back to a larger group. We give space for farmers to voice or show their interest. It was not uncommon to see two farmers leaning on a shovel or a hoe or rake talking. Topics of conversation ranged from a video game or book or sometimes an idea for the farm. I would have to catch myself from making any comments about efficiency. The purpose of the farm was more than growing produce. This process of give and take in dialogue and action is a core social skill.

We met weekly to farm so people became familiar with each other and shared greetings and learned about each other. It was noticed when farmers were missing. There was a concern. We talked about allowing each other to get on and off the bus at will. That everyone can quit, even if it is for one day. I underestimated the pull of the group. Initially I thought siblings of those with ASD would not be as engaged but I was wrong. They had a strong interest in attending each week regardless of who else was present. They were actively involved and voiced continued interest for next season. It was at that time I realized that each person had their own motivation for participating.

During the summer other activities flowed from the farmers. There was an on the side of the barn movie night with Buster Keaton in The General. The farming audience provided plenty of discussion during the silent film. Chicken races were also a hit. Simply put, a garden hose was used to make a circle. Farmers placed chickens in the center, and at the count of three, the farmers had to leave the circle. The first chicken that left the circle was the winner.

Cooking also became important. Farmers cooked together and we made some of the best potato chips from organically grown potatoes; squash pies; eggplant lasagna; and salsa. There was a strong desire to make familiar foods – or familiar enough with substituted ingredients. Farm goods that were easy to cook at home were also a favorite such as corn on the cob. There were questions on what to do with the kale or eggplant or different squashes at home. Food diversity is an area of opportunity to learn together. We will have to figure out how to incorporate it into the farm for next season.

Literature on social farming focuses on the measurement of outcomes (direct and indirect). Direct outcomes include therapeutic effects, educational effects, work inclusion, job creation. Indirect outcomes include the environment, landscape, biodiversity, direct selling, farm reputation, and farm viability (Di Iacovo, 2009). Positive therapeutic outcomes are common (Haubenhofer, 2008). Kay states that "physical activity provides an appropriate outlet for the energy previously spent in self-stimulating or destructive behavior" (1990).

An interesting observation is that current agricultural resources can allow for integration and inclusion. There are lifelong supports for agriculture available. Counties in Michigan, which had the duty in the past to care for those with mental illness, have co-operative extension services. These resources are open and available to support all abilities in a community of care. There could be lifelong community inclusion through agriculture. Inclusion builds knowledge. Sins of the past can be avoided and realities of today can be understood when people work together. This could be a move to acknowledge the exceptional people in the community.

Animals

In her 1995 book, "Thinking in Pictures: And Other Reports from My Life with Autism", Dr. Grandin wrote, "Being autistic has helped me to understand how they [animals] feel ... People often fail to observe animals" (p. 155). She attributes her success in animal science to her connection with animals; in discussing her discovery of one specific approach she developed to calm cattle at a slaughter plant, she explains, "All it took was a cow's eye view" (p. 156). It is through this perceived connection between people with ASD and animals, that we sought the farm. Many of the social farms for those with ASD include animals. The barn animals include goats, saddle horses, calves, sheep, pigs, and cats. There is a chicken yard, a turkey run, rabbit hutches, and a pond for ducks and geese. Some animals are kept as pets and others are used for their wool or for meat (Kay, 1990).

Our social farm was not too different, except that we did not have any animals for wool or meat. Our horses were therapeutic riding horses that welcomed petting. The chickens were well handled and easy for farmers to engage with. The goats were just goofy. Cats strolled the garden hoping for attention. Farmers enjoyed the animals. They knew the animal names. They actively handled the chickens, placing them in the garden to eat the bugs. They were a draw for the farmers and may have increased participation. As mentioned earlier, there was overall a reduction in anxiety, in which animals may have played a role (Fourtney, 2006).

Vocational Opportunities

Just as the farm can provide a venue for voice and for social skill development, it can also provide training and potential vocational opportunities to a much needed population. Individuals with ASD may feel isolated and excluded from society with little opportunities for meaningful work or positive social interactions (Giddan, 1993).

> Temple Grandin " I would offer a word of advice to all people who work with children or adult on the spectrum: develop talents that can be turned into jobs skills or hobbies. Social interaction will develop through an interest that can be shared with other people. Special education teachers often put too much emphasis on deficits and not enough on building on areas of strengths." (in Sicile-Kira Autism, 2004)

Activism for basic civil rights for the disabled culminated in 1990 with the passage of the Americans with Disabilities Act. As with antidiscrimination strategies in regard to race and gender, these guarantees were based on a normalization strategy (Bumiller, 1988). Applied in the disability context, the primary objective was to open opportunities in the workplace for the disabled so that they could assume the role of productive workers and consumers. Normalization prescribes acceptable behavior based on norms and relies on professionals to train their clients to follow the standards of nondisabled communities. Normalization was supposed to provide a mechanism to integrate those with ASD. However, vocational opportunities are extremely limited (Lattimore et al., 2006). The pressures for social integration that accompany these practices result in professionals devaluing deviant groups or accepting them only when they appear like members of the mainstream (McKnight, 1987). Kay states that for autistic people, who may be obsessed with rituals and compulsions and the maintenance of sameness at all cost, spending all day doing the same meaningless task may actually reinforce their autistic handicap. The farm life model for training offers an alternative. The number and variety of activities on a farm are endless, and even the most handicapped can be involved in important work and can respond to living harmoniously with nature (Kay, 1990).

Our farm focus was not vocational but it could be, especially through collaboration of a cooperative extension or other partners. However, the farm did build new skills sets around soil health, horticulture, animal care and cooking. The skill set was developed for all farmers, those with ASD and those without. The idea is not that the farm provides services and opportunities for one group but for anyone who wants to participate.

Research Hypotheses Addressed

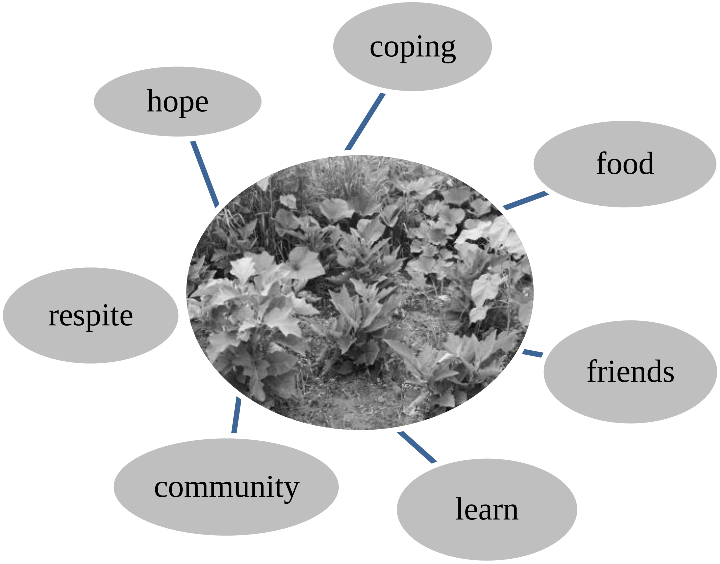
This section addresses the three original research hypotheses:

- Motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism.
- Social farming fills a gap left by the lack of institutional supports.
- As the farm is part of the surrounding rural community, social farming supports inclusion.

Agrarianism

One of the original research hypotheses stated that “the motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism.” First, the question should be whether farmers participated because of agrarian ideals, regardless if they have autism or not. To that, I would say “probably not”. I think we all came to the garden for our own motivations that were personal and maybe not even realized.

Figure 9: My Motivations for Social Farming



Literature also provides insight into motivations for social farming including, a direct respond to the needs of particular disadvantaged groups, an alternative to the intensification of agriculture, increased farm income or a place where the overall personal wish to carry out (alternative) professional practice in this field (Di Iacovo, 2009).

A social farm can also be a response related to social justice and solidarity (putting personal values and beliefs into practice. (Di Iacovo, 2009) Another life-style choice is the Community Supported Agriculture (CSA) movement. Since CSAs came to the U.S. in 1986 there has been a considerable flood in food awareness and concern for the growing practices, distribution and consumption patterns inherent in industrialized agriculture. These food movements encompass a number of important environmental, economic and social concerns. Some of the many food movements include: organic food production, food safety concerns, local food, and community food security, along with an increase in urban agriculture initiatives. Care farming could become a new movement. These movements have in common the a need for critique, reform and even a re-visioning of farming practices; exploring organic alternatives; and meeting the challenges of agriculture, health and community (Pollan, 2010).

A CSA allows for more connection to one another at a more personal and local level than has been the trend post 1940. In our case the CSA is currently referred to as a UFO. It is an inclusion (universal) farming opportunity where those that participate get a share of what is grown. Even more so that in community supported agriculture, there is a shared sense of reconnecting with others who grow our food and other like-minded individuals who want to support a community and regional economy. This type of arrangement could increase a sense of togetherness and appreciation for each other, the land and the food it produces.

Agrarianism presumes that farming or ranching has special moral and political significance. Agrarian ideals assert that the activity of farming confers unique characteristics on the people and communities that practice it (Thompson, 2010). Hard work, self-reliance and openness to alternatives are keys to Berry’s vision of farming, and these values are also central to his philosophy of the moral life (Berry in Thompson, 2010).

For us, everyone farms, works hard and receives the rewards (blackberries, social events, and harvest). We started at the farm for a variety of reasons, some motivations agrarian in nature (alternatives to intense agriculture, social justice and lifestyle choices). I think farmers returned week after week because that they valued the hard work and the rewards; however they define "rewards" for themselves. We also valued the agrarian stewardship of the farm. There was a strong care for animals (free range chickens used for eggs) as well as the organic methods used for crop production. There was a celebration of the wild blackberries when they were ready to harvest and a desire to keep them integrated in the farm as wild, in more of a permaculture approach. The discussion of continuing to source plants locally (for this year) and the pride in showing heritage brands of tomatoes also affirms a strong land stewardship.

Through the social farming process, the farmers worked together and built something together, something that had been difficult to attain – inclusion. Inclusion, simply the act of including, may not have one of the characteristics originally considered as an agrarian ideal. However, the agrarian vision may be broad enough to encompass inclusion. The farm was open and people felt welcome enough to bring other family members and friends and they also felt the openness to disengage or quitting.

> When I went to pick up N yesterday, he didn't want to garden so he wrote a note saying "I quit. N". That is a great reminder that Tuesdays are meant as an open farm day and that you can come or "quit" for any day. Of course we miss you but there is always the next week. That is one thing about farming – there is always plenty to do.

So, reconsidering the issue of social farming and agrarianism, I find that it may not be agrarianism that brings people to farm together but it is a result of farming together weekly over an entire season. The values of hard work, stewardship, and even the individualism of farming over other more corporate choices, are all agrarian ideals. Perhaps, the idea of the farm representing a social entrepreneurial activity would also qualify. Thompson also states that agrarianism is tied to democracy through a quasi-populist argument whereby farming families are thought emblematic of “the people” that a democracy is intended to serve (2010). In this case, the inclusive environment of the farm could, and arguably should, be the people democracy was intended to serve.

Social Farming and Institutional Supports

In regards to the research hypotheses “Social farming fills a gap left by the lack of institutional supports”, I found that I used social farming as an attempt to fill this gap and I had previously tried other ways to find a network of support. In 2006, we started the MSU families for individuals with autism group. It was at that time we started hosting events for other families (picnic and art show). I also started to open up the farm to others such as Isabel’s preschool class and other families. We started the social farm in 2010.

Originally, I sought farming to integrate my son’s therapies into his natural daily life. His need for sensory integration, heavy work and his love of animals steered me to a farm setting. However, after reflection, I realized that the gap social farming was trying to replace was more than just another service or therapy, but that I sought out a structure to give my son and others a voice. Frustrated by experts dismissing my son at the local, regional and state-wide level, I was actually using the farm as a positive model for inclusion that respected all abilities. The paradigm shift (discussed above) set the stage for voice and a choice, and we, as farmers, became more engaged and empowered.

Social Farming and Inclusion

Considering social farming and community inclusion, I considered my networks; the amount and the diversity of relationships that were built around agriculture and around autism. My farm networks were a mix of family, friends, neighbors, and co-workers. They provided animals, expertise, fence building, tractors, modeling, seeds, transplants, and support. They brought ideas and a willingness to engage with the farm from the time we purchased it, through our learning and finally through our first harvest party (September 2011). At our harvest party, most were in attendance, a sign that they saw themselves as a part of the farm, not a compartmentalized service provider. They were vested in the entire process. This represented a "chain of connectivity" where expertise leads to contact which builds interpersonal familiarity, which can foster trust, based on experience" (Sligo, 2006).

In a study by Mailfert, she considered how social networks provided resource access to beginning farmers and to the extent to which new farmers from farm and non-farm backgrounds construct their networks (2007). Her research questions centered on the mechanisms through which networks function to produce resources. Is it through closure (Coleman, 1988), with strong, intimate, trusting ties providing the resources, or through openness (Granovetter, 1973), with weak ties providing greater access to resources such as economic information, or through both?

Using the model Mailfert created of a personal network, as a beginning farmer I examined the same three categories of resources (Tichy, 1981): (i) goods and services (land, buildings, livestock, loans), (ii) information and advice, and (iii) emotional support and encouragement (see tables below). In regards to the strength of the relationship, it includes the geographic connection (local v. non-local); if they were from a traditional farming family (farmer/non-farmer); the gender; and education (high equals some secondary education beyond high school).

Table 7: Goods and Services for Beginning Farmer Network

Identifier	Goods/services provided	Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated
G	Provide plants and seeds	Local organic farmer, neo-farmer, high level of education, male.	Neighbor
B	Horses, tack, contacts	Local farmer, woman, high education	Professional relationship
J	Chicks and materials	Non-local farmer, woman, high education	Work relationship
R1	Goats	Farmer, male, family member, high education	Family
R2	Building of the chicken coop	Non-local non-farmer family member, male, high education	Family
F	Fencing for animals	Mostly non-farm family, male, high education	Family

Table 8: Information and Advice for Beginning Farmer Network

Identifier	Info provided	Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated
G	Care, how to plant, seasonal issues	Local organic farmer, high level of education, male	Neighbor
B	Care, feed, handling of horses	Local farmer, woman, high education	Professional relationship – therapist for son
J	Care of chicks	Non-local farmer, woman, high education	Work relationship
MSU Extension	Pasture safety and feed	Local non-farmer but in farm business (pasture –M), high education	Proximity
S	Feed questions, animal issues (all but horses)	Local non-farmer but in farm business (owns feed store), (unknown education)	Proximity

Table 9: Emotional Support for Beginning Farmer Network

Identifier	Provided	Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated
S	At the start to consider a farm	Non-farmer, non-local, woman, high ed.	Professional
P	Farm life is good	non-farmers (non-local) who had farm experience and thought farm "virtues" were good, especially for kids. Low education	Family

Table 10: Summary Table for Beginning Farmer Network

	Local/not	Far/neo/non	Male/fem	Family	Local Weak tie	Non-local weak tie
GS	2/4	3/1/2	4/2	3	2	1
Info	3/2	2/1/2	3/2	0	2	3
Support	0/2	0/0/2	1/1	1	0	1
SUM	5/8	5/2/6	8/5	4	4	5

In general, links can have a wide range of possible strengths, but for conceptual simplicity —these are organized in two types: strong ties (the stronger links, corresponding to friends and family), and weak ties (the weaker links, corresponding to acquaintances) (Kleinberg, 2010). As a beginning farmer there was plenty of dispersion among the players. There was a mix of local and non-local assistance and a range of farmers and non-farmers as well as male and female. The social relationship was also across family and local and non-local ties. Overall, however, there were more weak ties than strong family ties as expected with a new "neo" farmer (Mailfert, 2007).

The local farmers (not neo-farmers) were not really helpful for us. They are nice neighbors but never reached out to offer services or advice. In general, they were not supportive of our choices, as a small organic farmer and one that has animals. They too have gardens but do not use similar practices. These local farmers were exclusive. Whether it is scale, that we "work" off farm too, or that we are unconventional; local farmers were not supportive.

A second and parallel network that was being developed was my network for helping and treating Harry with his ASD. I attempted a similar network approach as above:

Table 11: Goods and Services for ASD Network

Identifier	Label	Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated	Social Farm?
S2	OT	Non-local, non-farmer, woman, high ed	Therapy	
M	SL	Local, woman, high ed.	Therapy	
N	SL	Local, woman, high ed.	Therapy	Yes
S3	MD	Non-local, male, high ed.	Therapy	Aware but not participate
ST	Teacher	Local, woman, high ed.	School	
H	MD	Non-local, female, high ed.	Diagnosis	

Table 12: Information and Advice for ASD Network

Identifier	Label	Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated	Social Farm?
E	Mother of son with ASD	Non-local, woman, high ed.	Email	Yes
L	Mother of son with ASD	Local, woman, high ed.	Email	Aware but not participate (lives on a farm)
S3	MD	Non-local, male, high ed.	Doctors office	Aware but not participate
B	Family	Non-local, female, family, high ed.	Family	Yes

Table 13: Emotional Support for ASD Network

Identifier		Strength of social relationship (local/non-local, farmer/non-farmer, gender, education)	How relationship was initiated	Social Farm
F2		Non-local, women, high ed	Family	Yes
C		Non-local, woman, high ed	Work	Aware but not participate

Table 14: Summary Table for ASD Network

	Local/not	In my farm/no	Male/fem	Family	Local Weak tie	Non-local weak tie
GS	3/3	1/5	1/5	0	3	3
Info	1/3	2/2	1/3	1	1	2
Support	0/2	1/1	0/2	1	0	1
SUM	4/ 8	4/8	2/10	2	4	6

The ASD network was predominately not local and was especially female. There was limited family involvement. A comparison table of the beginning farmer and the ASD network is below:

Table 15: Network Comparison Table

	Local/not	Continue to SF	Male/fem	Family	Local Weak tie	Non-local weak tie
ASD	33% local	33% part of SF	17% male	2/12=17%	4/12= 33%	6/12=50%
BEGIN FARM	38% local	31% part of SF	62% male	4/13=31%	4/13=31%	5/13=38%

Knowing this is only one sample, and it is mine, still provides some interesting observations. Both my networks for beginning farming and ASD were predominately non-local. This makes sense to me because I was, in both cases, engaging in something new and I was seeking assistance on a broad scale. The male/female ratio is very different. In farming, my networks were 62% male but with ASD it was only 17% male. Women do predominate in the field of therapies for my son, I seek out other mothers with children with ASD as support, and my support in my family is predominately female. I was surprised to see that there was a higher percentage of family assisting with beginning farming than my ASD network and in both networks, my family is rather low (15-30%). Both beginning farming (in a non-farm family) and having a son with a disability is outside of the "norm". Both can have issues with being an outsider looking in and therefore the need to establish other networks that have more commonalities than geography or family.

Perhaps I recognized this separation from others during my own network development and as a result, became more action oriented and found it necessary for my own growth and development to begin a group at MSU or to begin a farm. I brought this community together to meet my needs as well as my son’s. Inge describes agrarianism as the cultivation of the soil that "has within it a positive spiritual good" and that the farmer "has a sense of identity, a sense of historical and religious tradition, a feeling of belonging to a concrete family, place, and region, which are psychologically and culturally beneficial" (1969). Perhaps I was looking for a model community where I could find order out of chaos. I was a non-farmer, so I may have bought into the rhetoric or the fantasy of rural life. However, in a time where I particularly felt alone, maybe a farm provided a sense of place.

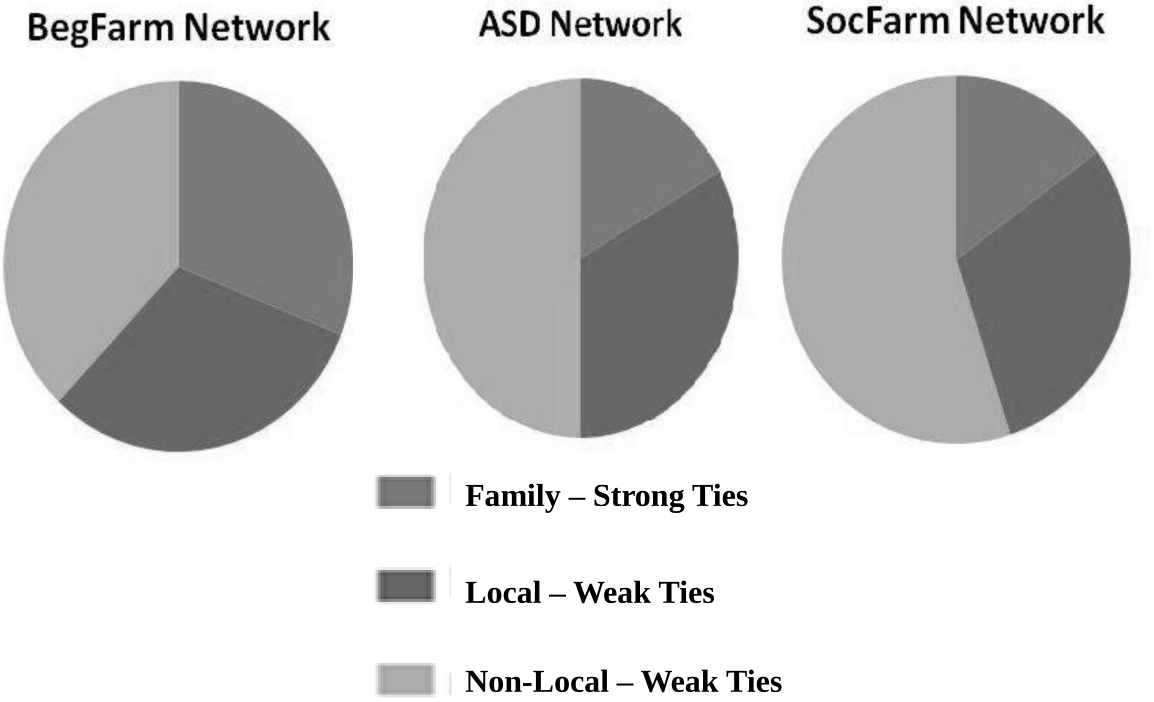
One other observation was that 30% of the networks for ASD and beginning farming continued to be engaged in the social farm. There was an overlap and sharing between the networks and others, a building of social capital: “features of social life - networks, norms and trust - that enable participants to act together more effectively to pursue shared objectives" (Putnam, 1993). All were considered farmers, the same as families and individuals with ASD and their siblings. This eclectic group worked through planning, socializing, planting, harvesting, pests, raccoons, and any other issues that arose on the farm. The farm was more than a direct marketing strategy (e.g., a CSA), but rather a UFO – universal farming opportunity - that allowed a diverse group of farmers to engage in a deep and embodied way (Delind, 2007).

The table below compares the three networks. Social Farm networks are those that engaged in the UFO for the Summer of 2011 (excluding myself, Joel and our kids). There were 30% of people that participated that were local, while 55% of the people were non-local. As Harry is engaged in other networks for services, his contacts with others outside the immediate geographic area is broader. Families travel for services. In the case of the farm, families traveled to the farm and they did not have any background in farming.

Table 16: Comparison Table of Networks

	Local/not	Cont to SF	Male/fem	Family	Local Weak tie	Non-local weak tie
ASD	33% local	33%	17% male	17%	33%	50%
BEGIN FARM	38% local	31%	62% male	4/13=31%	4/13=31%	5/13=38%
Social FARM	30% local	**0% farm background**	50% male	15%	30%	55%

Figure 10: Comparison of Networks



The commonality between the networks was the need to build ties, even geographically dispersed. Seeking and building ties takes time and effort and doing so across distances is difficult. This highlights the importance of finding ways to facilitate the building of weak ties with members of the local community, though it is unrealistic to expect that newcomers to farming, and social farming in particular, will form strong ties in rural communities where tolerance of diversity may be low.   Given the evolution of farming systems and increased need for alternative opportunities for those on the spectrum, these diverse groups could benefit from capacity-building initiatives that encourage each other to move across ‘boundaries’ to access resources in innovative ways. The overlap of these networks is a multidisciplinary or transdisciplinary approach that integrates and synthesizes many different perspectives in the co-production of knowledge (Aeberhard, 2008; Costanza et al., 1991; Kessel, 2008; Pohl, 2007; Walter, 2007).

Literature on care farms networks focuses on a variety of regional and national professional networks that tend to define stakeholders as “farmers, agricultural and health organizations, financiers, political organizations, and scientists” (DiIacovo, 2009). Also discussed are partnerships which represent health providers and the county as “partners in recovery”. The separation of client or service user to provider and practitioner is consistent and the former is not included in the discussion of networks.

Literature on social farms also discusses the “community experience”. This can be represented as those with disabilities on the farm gathering together “all the community meets regularly at lunch and dinner time” (Di Iacovo, 2009). Community also refers to those living outside of a social farm. “People who live on small farms near small communities know their neighbors and may have close ties with them through all the institutions in the area on which the population is dependent. Integration into the community is very natural as everyone shops at the one or two hardware, grocery, or seed stores in the village, or has lunch at one of the three restaurants. Integration by residents of Bittersweet Farms is equally natural. By shopping locally, eating in local eateries, having tables at local festivals, running in the annual local race, helping a neighbor plow a drive, hiking and skiing in the nearby park, swimming at the quarry, and going to village churches on Sunday, residents become familiar faces and a real part of the community" (Kay, 1990). The community participates in the farm when "neighbors are frequent visitors to the farm as they come to the Fronthouse Tearoom or the annual chicken barbecue, come to work on construction or repair projects, drop off their surplus rabbits or ducks, come to buy vegetables or crafts, or to bring their lawn mower or rototiller to be repaired. Many just drop in to see a friend or say hello" (Kay, 1990).

To address the research hypotheses, "As the farm is part of the surrounding rural community, social farming supports inclusion", it was shown that the immediate surrounding community (via networks) was not, by geography alone, supportive of the social farm. Recall that in the Networks section at the beginning of this chapter, 55% of the assistance for the social farm was from non-local, non-family supports.

However, social farming can support inclusion through the opportunity of voice and choice. As stated earlier, inclusion is more than physical space. It is more than Harry learning to conform. There is a bigger duty to society to "get it", and give him his rightful place where he can live his life within the culture of a community, a caring culture. This is why inclusion is a human rights issue.

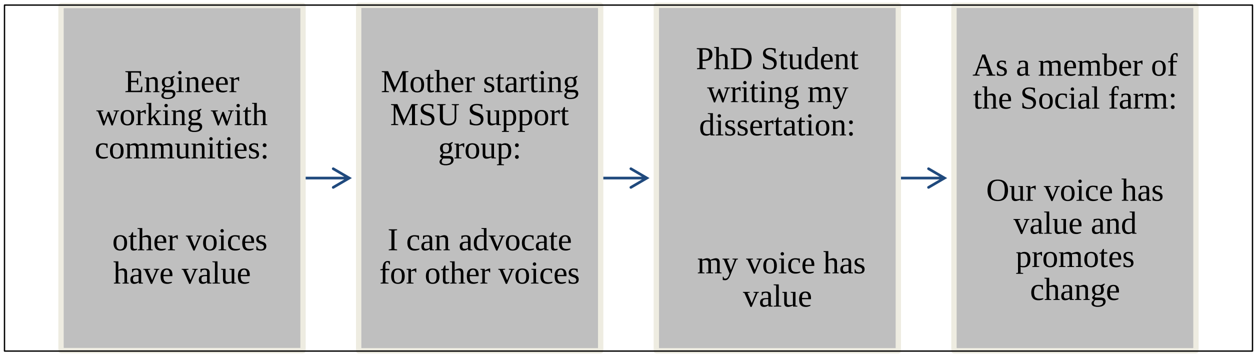
Therefore, social farming can support inclusion, depending on the framework for which it chooses to operate and how participants choose to engage. (See Paradigm Shift)

Gender and My Journey

I also wanted this research to explore my experiences as a mother with a son on the autistic spectrum from diagnosis to developing the universal farming opportunity. This was a reflexive account of my own experiences situated in this sub-culture. Through reflexivity, journaling, and looking at archival records, I began to understand my own story and developed my own voice. I hope my insight helps to change some of the perceptions around issues facing those families with ASD (Jones, 2005).

Through this process I my perception of self and my voice changed (see Figure below).

Figure 11: Change in Voice



It was at the beginning of my graduate school courses that I wrote and began to accept other voices and other ways of knowing.

> I realize that is time to broaden my view of knowledge. I am not ready to abandon the scientific method even with the inherent problems with dualism. Perhaps I am seeking an advanced degree outside of the “real” sciences because I agree with Weber"[w]ith the progress of science and technology, reality has become dreary, flat, and utilitarian, leaving a great void in the souls of men which they seek to fill by curious activity and through various devices and substitutes."

As I became more comfortable in my own knowledge, I was able to reach out and begin to advocate for others:

> One thing was clear: times have not changed (enough). We formed a group for others on or near campus: Families of children with autism

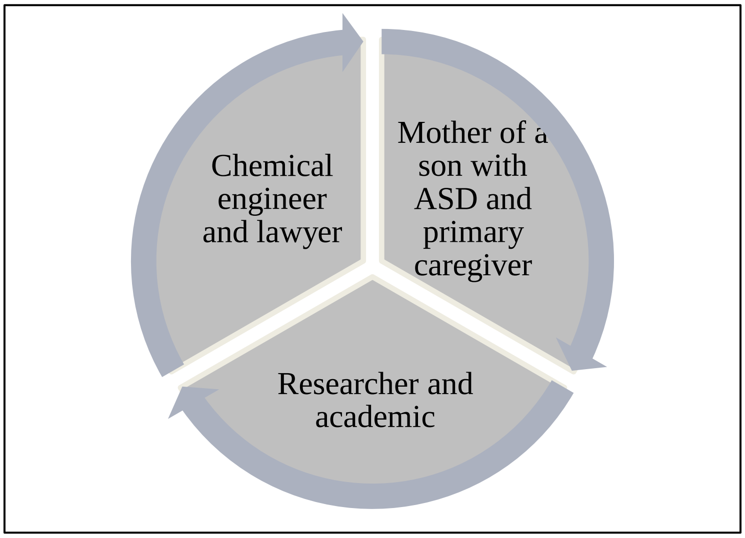
In this process, I realized that I am a knowledgeable and empowered woman. During my dissertation process, I struggled with autoethnography as a sole method for my research. In my dissertation proposal I offered to perform interviews with other farms, especially those with individuals with ASD. Although I was curious about the other farms, I was secretly looking for confirmation on my own thoughts and insights. Confirmation is not bad for research, except when it is used to conform to the established research paradigms. By waiting for interviews to be completed, I did not own my own findings. I was afraid to go too far out on a limb. Then, one day I was sitting on my bed with papers strewn about and I realized I didn't need any other interviews to bolster my findings. My voice and my knowledge were enough for my dissertation to stand on. In fact, a dissertation that claims to value different ways of knowing, but does not, in the process, support that voice, is insincere.

Finally, through my research findings, I realized that the social farm was not only about meeting my son's individual needs but as a partner with others in building an inclusive and intentional community. The farm was not about isolation for me. It was about relationships. When we are out in the garden together, it was not a gripe session but a growing session. It was learning together, real inclusion – plant, cook, struggle, learn, and share. That is the real data.

Standpoint

I have a unique standpoint. A standpoint is a place from which human beings view the world. Standpoint theory supports the notion that the perspectives of marginalized individuals can help create more objective accounts of the world (Harding, 2001). So it is my position as a mother of a son with ASD that I view the world. I have experiences and insight that is not experienced by many other members of society. I wanted to give this voice. There are some stories and insights that families with atypical developing children could not imagine and that my son was too young to understand. I also feel my position as a researcher/academic gives me a unique standpoint as well as a woman who has, over time, developed many masculine leadership traits due, in part, to my undergraduate education and 10 years as a chemical engineer in the refinery world.

Figure 12: My Unique Standpoint



Power

I am not only Harry's mother, but his primary caretaker and advocate. Glenn (1994) argues that mothering is closely connected with gender, not because of women's biological characteristics, but because of stratification and hierarchy within a society that devalues women and children. Mothers who have children with autism play a major caregiving role not because they are biologically more suited for the job, but because they live in a society where the division of care work is hierarchical. I did not consider myself on this hierarchy, but even though Joel and I both worked full time, I pursued therapies and options for Harry:

> I was at a loss of where to find services to help him. I went to the Employee Assistance center at Michigan State University. I wondered if they had any recommendations.
>
> I saw a brochure for hippotherapy on the corkboard. I told his therapist that I was thinking about horse therapy. She said I should check into it. At home that

> evening, I tried to find that number from the billboard without luck but I did come across CHUM therapeutic riding. Harry still rides there today.
>
> I went to Dr. S for years, often alone or with Harry. It was not until Fall of 2011 did Joel go to Dr. S without me. I had made the appointment.

I was usually one of many mothers with their sons attending therapies:

> Three other mothers and I sat around this baby monitoring listening to our kids. We didn't speak. We didn't laugh. We never wanted to offend each other.

I was actively involved in his school:

> Harry and I lucked out in kindergarten. We had Mrs. Woods. She was magical. She let me into her classroom where I participated every Friday.

Joel did all of Harry's coaching and was den leader (an accepted masculine role):

> This was also the first year Harry tried team activities like flag football, soccer, and t-ball. Joel was the coach. That was the agreement between us. If Harry participated – so did Joel. I think that is where Joel started to have a stronger voice for Harry's inclusion. Joel always made sure that there was good sportsmanship and that everyone played. Oh, and that there were snacks. To date Joel has coached every year, multiple sports and including den leader for cub scouts.

There is structural power in most of these setting including the therapists and at school. As a caretaker, I was expected to receive services without question. As a mother I felt I did not have control or influence (power over) over the behavior of others such as therapists, school, or to make changes in group meetings. In some ways I have a very masculine approach to people. I am a trained engineer and attorney. I was used to being able to confront and challenge situations. However, I needed to collaborate with providers and school administrators – to build relationships because they had the control – from setting meeting dates to the IEP to offering solutions. I learned to do what was socially acceptable for a mother in my position. I tried not to be confrontational. Was my concern for others one of pragmatism or I am somehow, because I am a woman, more concerned with these relationships? For women, the integration of rights and responsibilities takes place through an understanding of the psychological logic of relationships. (Gilligan, 1993)

> I tried to be positive but at the end of our session, I walked the kids to the car and then called Joel. I called outside the car because now I was crying and mad as hell. I told him what happened. I did not know it, but Joel went to the music school and confronted the man.

I used third party resources to support my position an advocate for my position:

> Every item that Dr. S recommended was implemented. The visit with Dr. S was $150. The coffee cake was zucchini chocolate. The change in his classroom – priceless.

I felt compromised to be so submissive in order to receive assistance and services. I definitely was not in a position of power. I really felt I had one of three choices, to conform, to be quiet, or to act. Through the organization of the social farm, I decided to act. Working on the farm, I was more in a position of power (my farm/my rules!). However, a thought running through this dissertation effort was the realization of a needed paradigm shift – from an expert/client relationship to a collaborative effort. This reduced power issues, to some degree. As relationships continued to grow, power became less of an issue. When efficiency was removed as a primary motivation for farming, power issues were also reduced. Farmers with different abilities were accepted at any task.

Unintended Consequences of Social Farming

Frances Cleaver (2003) said that increasing women's participation without considering their multiple obligations may cause more harm. Extrapolating this idea to the caregiver role which has been, in my experience, primarily women, the question is an important one. Did the farm add additional burdens to the caregivers? Did it do more harm than good? Any new venture can have unintended consequences and the farm was no exception. As I focused on the needs of the individuals with autism and their siblings, I did not consider the caregivers –

mothers, grandmothers and fathers. There were added burdens (unintended consequences) to the caregivers because of the farm, from adding another activity (time) to their plates; adding cost of transportation; having to prepare and deal with choices (it is easier just to play a video game); and having to prepare new (and unfamiliar) food at home.

Transportation became one of the first and major issues. None of those that participated could drive – either for their age or lack of license. Caregivers were already stretched and it was difficult to drive out regardless if it was 2 miles or 20 miles, each-way (the range of distance of the participants). The added time for driving took away other opportunities for the caregivers. Caregivers who were driving could not tend to other family obligations and could not tend to their own needs. Because the farm met weekly, it was a large commitment of their time, a burden that I did not consider.

I began to offer rides – from MSU or home pick-up or drop off. I could split with the caregiver so they were not burdened both ways or alternate with others – others would give someone a ride home, my husband would drive some home. But transportation was an issue every week. Given that, few did not miss a week at all.

The ride provided an opportunity to prepare for the farming – by talking about how things looked – how much things had grown and whatever work was done over the weekend, like extra weeding or watering. If I sensed uneasiness with the transition I would talk about the animals – how the chickens were doing and that they were looking forward to getting to the garden. I would help lay out the structure of the evening – if there was going to be a movie or not, what was ready to be picked (or checked), and if we were going to cook at all. Rides to the farm were very positive. If caregivers had done some preparation already, the transition to the car was smooth. If caregivers had not done the preparation, then it could be difficult.

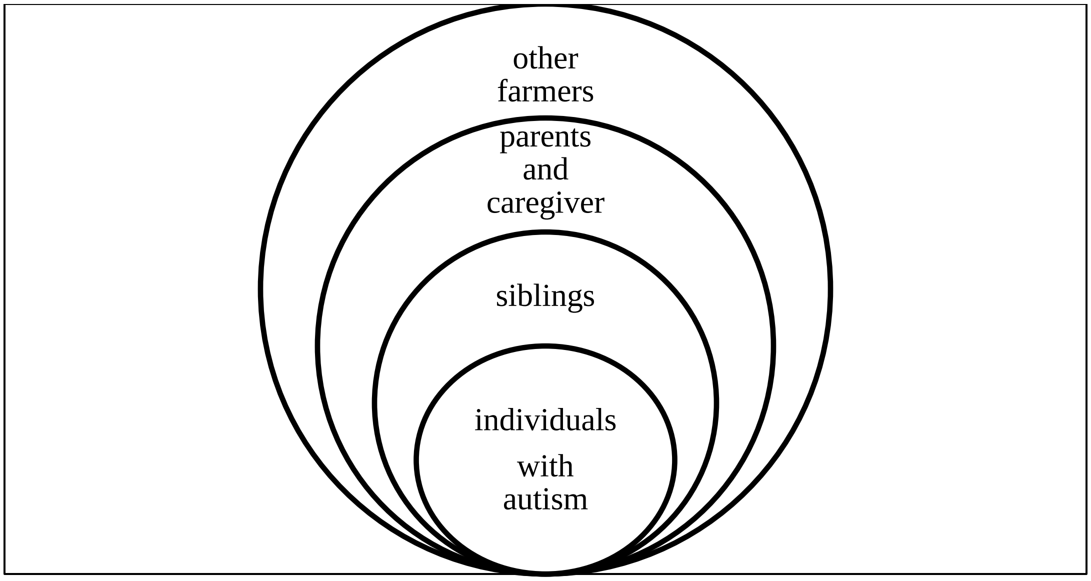
Difficult is a tough word to use here but it is true. If someone does not want to go to the farm, the caregiver is a bit embarrassed because they asked for a ride. The person may have a melt down and although I am very comfortable with it, they are not. It is very hard to understand voice in this context – there is anxiety for the transition, there may be concerns leaving their current activity (‘SpongeBob’ on TV), there can be some “discomfort” with the activities on the farm, especially if one is not accustomed to work. But there could also be fear of the unknown and the lack of structure that the farm brings, or the fact that they just don’t like farming or the other people involved. They may have a hard time understanding or appreciating delayed gratification. They might not like the smell or the sounds at the farm. This can add to stressors already present in the family or from school. No one wants another activity that goes poorly, has to be supervised, or adds to the low self-esteem of the participants.

The ride home was more of a celebration. Participants wanted to take something with them – whatever we had grown or cooked. But many farmers were not the kind of people that would run in the house with exuberance – they would walk into the house holding the ripe and ready to eat vegetable with an expectation that it would be converted to food.

Unintended Food Consequences

Many CSAs ask for volunteers. In my case, the farmers were the volunteers but the caregivers did not have the time or interest to volunteer. Caregivers did not hover, they let the young men and women participate without their oversight. Was this respite for the caregivers or empowerment for the farmers? There was definitely trust in the environment of the farm.

Figure 13: Support Structure



Farmers wanted to cook the food. So we cooked it and sent it home. Farmers wanted to bring raw fruit and vegetables home. Caregivers would ask what to do with it. There was unfamiliarity with kale or summer squash or eggplant and the caregivers would ask me how I would prepare it. There was a push to prepare food from the farm regardless if they choose to eat it or even try it after it was prepared. They wanted to cook it and take it home regardless.

Economics and Social Farming

It would be unfair to discuss my journey to social farming without positioning myself as a white, Midwesterner, academic, from a blue collar family. I have certain privileges, many are unearned. It is from this frame of reference that I am considering how to consider economics. Other families may not be able to purchase and operate and support a farm that has little monetary return, in a traditional sense. However, evaluating the journey to social farming would be remiss not to include some consideration of economics.

Holism, a Greek word meaning all, whole, entire, total is the idea that natural systems (physical, biological, chemical, social, economic, mental, linguistic, etc.) and their properties, should be viewed as wholes, not as collections of parts. It is the idea of holism that economics should be considered. Holism is an approach that tries to address complex systems or “wicked” problems as discussed in Chapter 1. John Muir wrote "When we try to pick out anything by itself we find it hitched to everything else in the Universe" (Gifford, 2006). These foundations provide a systemic approach where ethical, aesthetic, spiritual, cultural and ecological criteria are as important as the technical and economic criteria (Bawden, 2000).

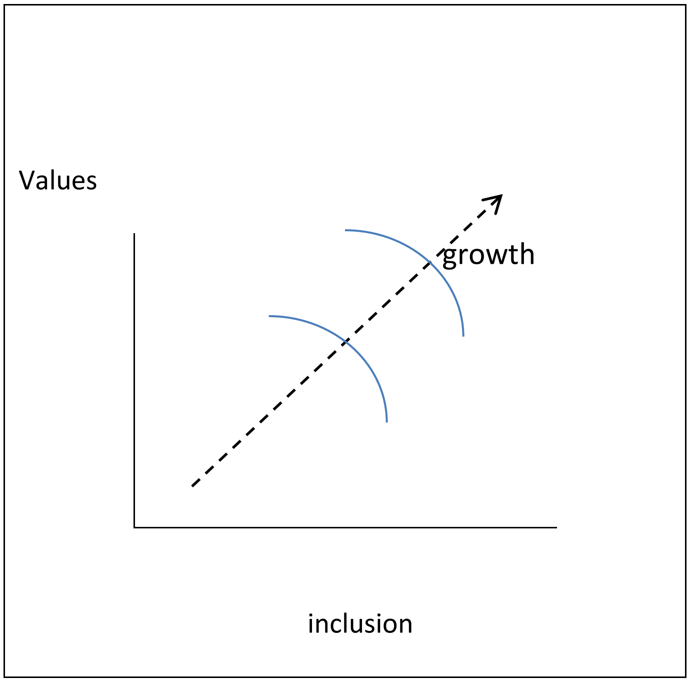
A review of literature that used both “Autism and Economics” revealed one article by Mohn (2010) which attempted to evaluate if “economic science is suffering from autism, a severe developmental disorder characterized by impairments in social relations and communication, combined with rigid and repetitive behavior.” One and only one statement of his paper is valid: “[this paper] may be seen as inappropriate by people whose lives are touched by this kind of misfortune”. This was the economic contribution in the area of autism.

There are many costs when raising children and raising a child with ASD is similar, yet different. Because of the lack of insurance, there are costs for therapies and early intervention strategies. There are costs of time and resources. There could be continued care costs or vocational training costs. The desired outcomes of the spending include an increased quality of life, equality and inclusion. I want my children to be active in society, to have opportunities for growth and happiness. From Johnson, growth is viewed as the creation of increased capacity to attain all conditions or situations and things which people find valuable. Equality is one condition we value (Johnson, 1986).

For those on the ASD spectrum, what are the values and the trade-offs? I propose that many of the values include income, health care, schools, vocational opportunities but comparing those with voice, choice, equality, or inclusion. There are combinations of say inclusion and other values attainable with a given amount of a society's capacity.

Although overly simple, the Figure below takes the lead from this work. (Bonnen, 1984)

Figure 14: Graph of Trade-offs



In the figure above, the vertical axis being other values (such as income, health care, schools, vocational opportunities, and personal safety) can be compared to the level of inclusion of those with ASD into society. Full inclusion or perfect integration into society is on the horizontal axis. The diagram shows that society can have trade-offs between the other values and full inclusion. The lines represent various opportunities for society to choose.

However, to move the opportunity lines in a positive way, there has to be growth. If state agencies or federal agencies are not moving the opportunity lines for those with ASD, it takes others in society to do so. The opportunity lines in the figure above can also be referred to as social indifference curves. Social farming can be the mechanism for growth if it also embodies the paradigm shift from service provider to collaborator in order to promote inclusion.

Social farming can be embraced through social entrepreneurship. Social entrepreneurship is argued to be entrepreneurship with an embedded social purpose" (Christie & Honig, 2006; Peredo & Chrisman, 2006; Peredo & McLean, 2006), "at least partially sustainable through trading" (Birch & Whittam, 2008; Chell, 2007; DTI, 2007; Haugh, 2007; Peredo & Chrisman, 2006; Tracey & Jarvis, 2007), and not being limited to a particular judicial / organizational form (Birch & Whittam, 2008; Chell, 2007; Mair & Marti, 2006). It is, therefore, seen more as an agent of change than a profit-seeking enterprise. Makhoulf states that social entrepreneurship can be distinguished by having three components: (1) an ability to identify a stable but inherently unjust equilibrium that causes me exclusion, marginalization, or suffering of a segment of humanity; (2) an ability to identify an opportunity in this unjust equilibrium and develop a social value proposition; and (3) willingness to take action in order to forge a new, stable equilibrium that releases rapped potential or alleviates the suffering of the targeted group. . .and even the society at large (2011).

As long as social farming embraces the collaborative model, then it can begin to alleviate the "suffering of the targeted group". Collaboration embraces voice and choice as discussed in Chapter 5. It is the belief that all people can contribute. In an article about a Texas turkey farmer, young men with mental disabilities were exploited by doing very difficult work for little pay. The farmer claimed to have included these individuals in family holidays and provided shelter and food. But it was found that those with the mental disabilities didn't choose this occupation and conditions (Jones, 2009). This issue of voice or choice can be skewed in this population because of the perceived inability to weigh alternative choices. Without understanding the options, those with disabilities may accept current conditions. Below is a piece I wrote in 2010 when I visited Peckham Industries.

> I thought one of the biggest conflicts that I am having with my research proposal is in the area of representation: What is knowledge and how do I represent it?
>
> If my research gives people voice and I use their own words or pictures or observations with no interpretation, then their knowledge is fairly represented. Once I begin to analyze or re-write or interpret their words and works, I change what is theirs for all to see. I feel that I am not giving respect to their ways of knowing, their knowledge. I become another researcher, filtering, when I want to help them tell their stories -their amazing stories – hidden to the causal observer.
>
> Last week I visited Peckham industries. The last stop on the vocational game in Lansing. My emotions were too strong to be objective. There, in a brightly lit warehouse, hundreds of people with disabilities sit at tables just a few feet apart – sewing. Sewing underwear for the army. An army of underwear. For full days – sometimes up to 10, they work in the warehouse receiving their deviated pay. A whole army of underwear and their civilian, disabled seamstress'.
>
> This would be hell on earth for my autistic son. The lights, the openness, the people, the sound, the lack of nature. "He could be a janitor" they said. Somebody please help me.
>
> I spoke to Esther. "There is no choice" I said. She said that her son can't say his preference. "I work today, mom. I paint today, mom." But both are represented as good and equal. She said we know choice when they have a tantrum. Then I take that as a no.
>
> For the entire day, I could not shake this feeling – I know where all my kids are going. My social skills group. The kids that come to the farm. Zoe, the dark haired autistic girl with a locker next to Harry's. Zoe would be a fine seamstress – what am I kidding! Zoe is quiet and don't cause a problem in class but that is the only reason she may make it as a seamstress. I want to give her an option. I want to give them all a choice. I keep crying.

Future Care Farms as Sustainable

Given the complexity of wicked problems, can our understanding of sustainability be used to protect the interests of diverse populations while embracing environmental and economic concerns? Sustainability is a social movement. It asks who decides, who benefits and who pays. The farm may meet the most basic needs as farmers have the opportunity and ability to learn, to work, and to connect.

Leopold highlights the many ways of knowing based on his lived experience. “There are two spiritual dangers in not owning a farm. One is the danger of supposing that breakfast comes from a grocery, and the other that heat comes from a furnace” (Leopold, 1949). He stresses knowing more than yourself but also how you are connected with and in the world. I would like to think that the diverse group of farmers that visited week after week at our farm developed that insight.

Leopold talks of wilderness as the freedom to make mistakes, the freedom to be different. This is also important for those with disabilities and their families – a place to be safe without judgment: freedom to work through an anxiety; freedom to disengage and crawl under something; freedom from other parents judging your child’s misbehavior; freedom for a sibling to say “my brother does the same thing” and not be embarrassed.

Sustainability encompasses a moral ideal: to act on what we feel we ought to do but only after taking the interest and preferences of others fully into account, especially looking towards the future (Singer in Bawden, 2000). For social farms to provide increase opportunity and inclusion, they could embrace this definition of sustainability and consider it over time (Willis, 2009). Using the paradigm shift discussed in Chapter 5, social farming will need new respect for different ways of knowing and new forms of engagement and power sharing. It will require new alliances and networks (both local and non-local) and an authentic interest in the co-production of knowledge. It is this challenge, then, to promote social farming though sustainability.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

Conclusions

Conclusions are organized around the basic findings including networks, therapies, and voice. Conclusions also address the three original research hypotheses. Finally, conclusions cover findings on economics and sustainability.

Paradigm Shift

From travelling down my journey to the farm it is clear that what is needed is not another service provider, but a paradigm shift. Comparing our experiences over our entire journey to the last year with the social farm brought up very poignant differences, differences in the approach, respect, and rights for those with ASD. The current model for those with ASD and society is a patient/practitioner model or a client/server framework. From there we see that this client/server framework is reminiscent of the expert model (we tell you what to do) that I was most familiar with in the environmental sciences. I propose a shift away from this model to a non-expert based, open, person-centered approach.

I believe the farm was a model for inclusion because we set a positive tone and used consensus or facilitated decision making. The outcomes of this setting included a long term engagement with interests of expanding.

Originally, we moved to the farm to integrate Harry's therapy and love of animals into his daily life. As the social farm developed, it was clear that we were not just trying to replace services; it was an outlet that provided equal access and decision making to all farmers, those with and without ASD. Sure, the farm has built an environment that can help address some ASD symptoms so that it is easier for those with ASD to become an active participant in all aspects. However, this alone is not the shift. The paradigm shift is that others, without ASD, change their perspective to accept the diverse abilities of others and to listen

Voice and Choice

The farm setting provided the opportunity for voice through decision-making, choices, and discussions. The farm offered an opportunity for trust building, and knowledge sharing, which brought new perspectives. Farmers were accustomed to talking to each other and, as a result there was an atmosphere of openness and inclusiveness. There are many choices on a farm, and only a few are time dependant. There was time to decide and figure things out.

The farm, as an outlet for open communication, could provide insight about ASD to each other perhaps reducing “socially created disabilities” (Higgins, 1992). Through sharing, farmers could gain information about the nature of ASD and coping strategies. This is a three-way street of recognizing differences; supporting differences; and inclusion.

Harry’s documented 7 things that he would like others to know about those on with ASD: do it their way; they may have a different way of looking at things; different people have different needs; look *with* them; be gentle; educate everybody about it; and don’t underestimate them.

Inclusion is more than physical space. It is more than Harry learning to conform. There is a bigger duty for society to “get it”, and give him his rightful place where he can live his life within the culture of a community, a caring culture. This is why it is a human rights issue.

Harry can actively participate in therapy but when institutions fail, individuals can still make the difference. Although there was yearly issues with the IEP, years where there were a partnership between the teacher and the parent were the most successful, regardless of the overall amount of conflict. Just as the farm can provide a venue for voice and for social skill development, it can also provide training and potential vocational opportunities to a much needed population.

Therapies and Animals

I believe the farm incorporated therapy into Harry's life. For those with ASD, there was an observed lack of sensory issues outside on the farm. There was an ability to try new things such as kale ("it tastes like a leaf"), or handle worms and chickens without issue, and yet farmers would wash and rewash hands during our cooking time, careful not to get anything on their clean hands. Perhaps with swings, and animals and the farm, there were plenty of clear choices and farmers could pick and choose activities depending on their interest and their need.

Working in a diverse group also built social skills in a natural environment as opposed to a therapy room or small classroom setting. This example demonstrates that the purpose of the farm went beyond growing produce. This process of give and take in dialogue and action is a core social skill and learning that skill is another purpose for the farm.

During the summer, other ideas for activities flowed from the farmers. Cooking also became important. Farmers cooked together and we made some of the best potato chips from organically grown potatoes; squash pies; eggplant lasagna; and salsa. There was a strong desire to make familiar foods – or familiar enough with substituted ingredients.

Many of the social farms for those with ASD include animals. Farmers in our UFO enjoyed the animals. They knew the animal's names. They actively handled the chickens, often placing them in the garden to eat the bugs. The animals were a draw for the farmers and may have increased participation. As mentioned earlier, there was overall an apparent reduction in anxiety, in which animals may have played a role.

Research Hypotheses

One of the original research hypotheses stated that the motivations for social farming extend beyond a safe place for children with ASD to a belief that there is a special connection between agrarianism and autism. Agrarianism presumes that farming or ranching has special moral and political significance. Agrarian ideals assert that the activity of farming confers unique characteristics on the people and communities that practice it (Thompson, 2010). Hard work, self-reliance and openness to alternatives are keys to Berry's vision of farming, and these values are also central to his philosophy of the moral life (Berry in Thompson, 2010).

For us, everyone farms, works hard and receives the rewards (blackberries, social events, and harvest). We started at the farm for a variety of reasons, some motivations agrarian in nature (alternatives to intense agriculture, social justice and lifestyle choices). I think farmers returned week after week because that they valued the hard work and the rewards; however they define "rewards" for themselves. We also valued the agrarian stewardship of the farm. There was a strong care for animals (free range chickens used for eggs) as well as the organic methods used for crop production. There was a celebration of the wild blackberries when they were ready to harvest and a desire to keep them integrated in the farm as wild, in more of a permaculture approach. The discussion of continuing to source plants locally (for this year) and the pride in showing heritage brands of tomatoes also affirms a strong land stewardship.

Through the social farming process, the farmers worked together and built something together, something that had been difficult to attain – inclusion. Inclusion, simply the act of including, may not have one of the characteristics originally considered as an agrarian ideal. However, the agrarian vision may be broad enough to encompass inclusion. The farm was open and people felt welcome enough to bring other family members and friends and they also felt the openness to disengage or quitting.

So, reconsidering the issue of social farming and agrarianism, I find that it may not be agrarianism that brings people to farm together but it is a result of farming together weekly over an entire season. The values of hard work, stewardship, and even the individualism of farming over other more corporate choices, are all agrarian ideals. Perhaps, the idea of the farm representing a social entrepreneurial activity would also qualify. Thompson also states that agrarianism is tied to democracy through a quasi-populist argument whereby farming families are thought emblematic of "the people" that a democracy is intended to serve (2010). In this case, the inclusive environment of the farm could, and arguably should, be the people democracy was intended to serve.

In regards to the research hypotheses Social farming fills a gap left by the lack of institutional supports, I found that I used social farming as an attempt to fill this gap and I had previously tried other ways to find a network of support. However, after reflection, I realized that the gap social farming was trying to replace was more than just another service or therapy, but that I sought out a structure to give my son and others a voice. The paradigm shift (discussed above) set the stage for voice and a choice, and we, as farmers, became more engaged and empowered.

Considering social farming and community inclusion, I considered my networks; the amount and the diversity of relationships that were built around agriculture and around autism. Network analysis showed that the immediate surrounding community was not, by geography alone, supportive of the social farm but this is similar to beginning farmer networks as well as my own ASD network. In all cases, the majority of the support and assistance was from non-local, non-family supports. It is important for social farms to identify their networks. Just being physically present in a rural community, does not mean that there is integration or inclusion.

However, social farming can support inclusion through the opportunity of voice and choice. As stated earlier, inclusion is more than physical space. It is more than Harry learning to conform. There is a bigger duty to society to “get it”, and give him his rightful place where he can live his life within the culture of a community, a caring culture. This is why inclusion is a human rights issue.

Gender

Through this process my perception of self and my voice changed. Finally, through my research findings, I realized that the social farm was not only about meeting my son’s individual needs, but also about acting as a partner with others in building an inclusive and intentional community. The farm was not about isolation for me. It was about relationships.

I have a unique standpoint. It is through this understanding and the use of my voice that I can impact the power differences. Through inclusive practices on the farm, power issues, to some degree, were reduced. As relationships continued to grow, power became less of an issue. When efficiency was removed as a primary motivation for farming, power issues were also reduced. Farmers with different abilities were accepted at any task.

There were unintended consequences of social farming for caregivers, including unintended food consequences.

Economics

Society can have trade-offs between the other values and that of full inclusion for all people. For conditions to improve there has to be growth. If state agencies or federal agencies are not moving the opportunity lines for those with ASD, it requires others in society to take those actions. Social farming can be the mechanism for growth if it also embodies the paradigm shift from service provider to collaborator in order to promote inclusion. Social farming can be embraced through social entrepreneurship.

Sustainability

Given the complexity of wicked problems, can our understanding of sustainability be used to protect the interests of diverse populations while embracing environmental and economic concerns? For social farms to provide increased opportunity and inclusion those populations, they could embrace this definition of sustainability and consider it over time (Willis, 2009). Using the paradigm shift discussed in Chapter 5, social farming will need new respect for different ways of knowing and new forms of engagement and power sharing. It will require new alliances and networks (both local and nonlocal) and an authentic interest in the co-production of knowledge. It is this challenge, then, to promote social farming though sustainability.

Recommendations

Some recommendations include:

Build new partners such as the co-operative extension services. These resources are open and available to support all abilities in a community of care. There could be lifelong community inclusion through agriculture. Inclusion builds knowledge. Sins of the past can be avoided and realities of today can be understood when people work together. This could be a move to acknowledge the exceptional people in the community.

Develop partnerships for a participatory action research plan for the farm. The last year on our farm has been focused on relationship building and proof of principle, as well as understanding the emerging areas for research. Effective partnerships require time and infrastructure support, for example, to establish and maintain trust, attend meetings, jointly participate in all phases of the research, and foster capacity building. I think the farmers are ready and there is a desire to do more. There is a desire for even greater community involvement in this process (Israel et al., 2005). The aim of is to increase knowledge and understanding of the social farm and integrate the knowledge gained with interventions and policy change to improve the health and quality of life of community members (Israel et al., 2005).

Continue to develop a strong foundation and learn from other farms. They each offer a different scope, with some providing opportunities for living, working, and socializing in rural settings with access to activities in neighboring towns and cities.

Be part of the change. If people learn to have a voice in a society that is oppressive, that treats them as those that have special needs but not equal rights, then they will push for change.

Consider sustainability for a framework to promote social farming. Wicked problems are complex. Analyzing the impact of social farming should consider all aspects found in sustainability: people, economics and the environment. This just may provide useful guidelines as we explore the role of social farming.

CHAPTER 7

REFLECTIVE ESSAY

Autoethnography is not for the weak. There are many levels of writing and reflection but the hardest part of the method for me was being authentic. Reliving some of the most difficult times brought back some very painful memories. It also reminded me of how far we had come.

In the process of the dissertation, I was nearly done with Chapter 4 so I had begun the analysis. I even made Mental Models that tried to explain my thought process and my relationships. However, the diagram was flat and uninformative. I realized I had to complete two sections in Chapter 4 – the school and the farm (year 1) before I could continue with my analysis. First, the discussion of school and inclusion was difficult. I have many report cards, notes, documents and strong feelings for those 7 years of Harry in school and I struggled with wanting to include all of it. However, as I began to reflect on important and meaningful times, my writing became clearer. The school section of Chapter 4 is not exhaustive but it is authentic. Second, I had to address my ‘Year 1’ on the farm. My writing, although factual, cast ‘Year 1’ as one without challenges. My omission was the discussion of the house foreclosure. I did not want to put this in my dissertation. Besides being incredible painful, it was embarrassing. But my commitment to the process of autoethnography and being honest with the story required it. Once I was able to write that small part, the others fell in line.

The other part valuable aspect of autoethnography, for me, was the empowering sense of voice. I felt that my graduate student career, although difficult at times, has solidified my Self. I listen to my Self more, but I also learned to listen to others.

I also believe that by changing my dissertation (and advisors), I was actually able to start the farm. Trying to do both a separate dissertation and a new endeavor would have been impossible. The farm alone took so much time and thought. I believe the farm is better because I have been able to reflect on it, be more intentional in my actions, and more aware of my surroundings.

The emerging design of this research process - the start with three simple questions knowing that there would be more to explore - is parallel to experiences from being a mom and with the farm. When I learned to be open to allow Harry to become whatever the person he is meant to become:

> I am forever grateful for Harry and the way he has taught me to see things differently and to embrace our own differences. I think by being open to letting Harry define himself, he was able to build his self-esteem. He does not view autism as “bad”, just different. I don’t either.

and when I relaxed in the garden because it is more than just growing food:

> Those two were talking more than filling that wheelbarrow! More than one dumped a wheelbarrow before it made it to the garden. It was a slow process, but with social farming, you have to know that efficiency is not the goal, at least that was what I kept telling myself.

Then, I became open to discovering and learning about myself.

Finally, I will be forever grateful for the new knowledge I developed over the dissertation process. Recognizing my networks was insightful, but realizing the need for a broader change in approach on the farm and in society was a watershed moment. I will never consider the farm as an outlet to those with ASD but as a community experience that benefits all who participate. With a foundation of inclusion, these farmers can provide education to those willing to listen. And hopefully this movement will extend to further action and policies that support human rights for all people, especially those with exceptional abilities.

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